Psychosocial and physical factors of importance for recovery from curative colorectal cancer surgery among persons ≥80 years old: a mixed method study

by

Kristina Sundt Eriksen

Thesis submitted in fulfilment of the requirements of the degree of
PHILOSOPHIAE DOCTOR
(Ph.D.)

University
of Stavanger

Faculty of Health Science
2023

University of Stavanger
NO-4036 Stavanger
NORWAY
www.uis.no

ISBN: 978-82-8439-171-7
ISSN: 1890-1387
PhD: Thesis UiS No. 706

Acknowledgements

The research for this thesis was conducted at Stavanger University Hospital from 2015-2023. I would like to acknowledge the research department at Stavanger University Hospital for funding my doctoral fellowship.

This thesis was made possible through the invaluable help and support of many individuals.

In particular, thanks to the participants for willingly contributing in interviews and answering questionnaires. The research would not be possible without their contributions.

I extend my gratitude to my supervisory team who were encouraging, patient and wise when guiding me in my research. I hope to model this method with my future students. They complement one another to form a particularly successful supervisory team. My main supervisor, Kirsten Lode, supported me unwavering and unconditionally throughout the PhD process through the sharing of knowledge in areas such as health research, methodology and cancer research and through excellent supervision. My co-supervisor, Sissel Iren Eikeland Husebø, provided supervision from the perspective of the greater picture, and presented insightful details, which caused me to reflect upon new aspects of my research, in addition to sharing her knowledge in nursing science and methodology. My co-supervisor, Hartwig Kørner, guided me on the clinical aspects of the research through his expert knowledge of colorectal cancer patients, and as well as his methodological knowledge. I thank all of the members of this team for their continuous encouragement.

I would like to express my gratitude to the members of the research groups HEVHELSE at the University of Stavanger and 'The research group for nursing and healthcare science' at Stavanger University Hospital for their encouragement, discussions, feedback, and support.

I am additionally grateful to my colleagues for their support on my PhD journey. To my colleagues at the Department of gastrointestinal surgery at Stavanger University Hospital I give thanks for their interest in my research, as well as their kindness, support and many clinical discussions. Special thanks to the nurse manager, Tommy S. Brakstad, for his support. I would also like to acknowledge my fellow PhD students for their fruitful discussions and reflections as well as the light-hearted atmosphere. Special thanks to Marte Johanne Tangeraas Hansen for supporting me and ensuring her availability for discussions, as well as for acting as my partner in crime.

I would also like to thank Une Størner and Inger Johanne Bergerød for their feedback on my seminars.

I am profoundly thankful to my family and close friends for their support throughout this journey. I could not complete this thesis without their support, counsel and understanding. Special thanks to Elina, Pernille and Ørjan for their patience and inspiration, and for reminding me that there is more to life than work. Thank you!

Kristina Sundt Eriksen

Stavanger, March 2023

Summary

Background: Colorectal cancer is the third most common cancer worldwide. Colorectal cancer can be a fatal disease accompanied by suffering if untreated. Surgery is the mainstay for cure and is considered safe for patients of all ages. The median age of diagnosis is approximately 72 years in Norway. With the increase in the older population, it is likely that there will be an equivalent rise in the incidence of colorectal cancer. However, older persons represent a heterogeneous group of patients ranging from patients in good health to patients with increased vulnerability to treatment and complications.

An excessive 1-year post-operative mortality rate has been observed among patients aged ≥80 years compared to their younger counterparts. After a year, the 5-year survival rate equals that of younger patients. With improvements in diagnosis and treatment in recent years, more patients are living beyond cancer treatment and into recovery. However, for patients aged ≥80 years in Norway, follow-up is determined individually outside systematic follow-up programs. Hence, there is limited knowledge on patients' experiences and perceptions regarding recovery after discharge.

Objectives: The overall aim of this study was to investigate the psychosocial and physical factors that are important for recovery after curative colorectal cancer surgery among persons aged ≥80 years. The following aims were formulated for the different studies:

- To explore the experiences of individuals aged ≥80 years recovering from surgery for colorectal cancer and the challenges they may encounter after discharge from hospital
- To explore the associations between sense of coherence, perceived social support, and demographic and clinical characteristics among survivors ≥ 80 years treated for curable colorectal cancer.

- To explore the experience of persons ≥80 years of age during recovery up to two years after curative colorectal cancer surgery

Methods: This project utilized a multiphase mixed method design, with the studies being conducted sequentially in their respective phases. Qualitative and quantitative methods were applied separately in the different phases and comprised the following: 1) qualitative interviews of colorectal cancer patients ≥80 years old (n=10) newly discharged from the hospital after surgery, 2) a quantitative cross-sectional survey of persons ≥80 years (n=56) treated for colorectal cancer 1 to 5 years prior and 3) qualitative interviews of persons ≥80 years old (n=18) treated for curative colorectal cancer 1 to 2 years prior.

Results: Recovery from colorectal cancer among persons ≥80 years old appears to be challenging for most in the short term, where psychosocial and physical problems and a lack of information made the recovery more challenging (Study 1). Sense of coherence, that is, coping capacity, was found to correlate with age, physical function and the need for homecare nursing. Perceived social support was found to correlate with re-admission, age at time of surgery and gender (Study 2). Long-term recovery was revealed to be a complex process influenced by the lasting effects of the surgery and resources at the persons' disposal, in addition to other factors such as additional health issues (Study 3). The follow-up care provided was lacking in different areas (Studies 1 and 3). The merging of findings across the recovery process of older individuals after colorectal cancer surgery was found to be a complex affair affected by the older person's sense of coherence and resources.

Conclusions: This thesis demonstrated that recovery among persons aged ≥80 years can be a complex process over a longer period with several psychosocial and physical factors influencing it, the most important of which were the experience of reduced function, occurrence of symptoms and complications, and support from family, friends or healthcare services. The thesis also revealed an opportunity for

advancement in follow-up care for older persons in recovery related to care coordination. Additionally, follow-up should be directed towards the management of experienced symptoms and complications and assistance in the management of comorbid condition to minimise their impact on recovery from curative colorectal cancer surgery.

Abbreviations and definitions

ASA	American Society of Anesthesiologists grading system
COREQ	Consolidated Criteria for Reporting Qualitative Research checklist
CRC	Colorectal cancer
ECOG	Eastern Cooperative Oncology Group
ERAS	Enhanced recovery after surgery
GP	General practitioner
MOS-SSS	The Medical Outcomes Study-Social Support Survey
SOC	Sense of coherence
SOC-13	Sense of coherence scale with 13 items
SPSS	Statistical Package for Social Sciences
STROBE	Strengthening the Reporting of Observational studies in Epidemiology checklist
TNM	Tumour-node-metastasis

Accordion severity grading system – Grading system for postoperative complications

Contents

List of Figures

List of Tables

Part I

1 Introduction

Recent improvements in cancer treatment have resulted in more patients living beyond treatment and into recovery (Haugan & Rannestad, 2014). The benefits of treatment, especially among older persons, depend on supportive care in short- and long-term recovery such as rehabilitation, management of comorbid conditions, surveillance and management of psychosocial effects (WHO, 2020). Additionally, significant challenges can occur in recovery that are often avoidable through collaboration between health and social care systems (EU, 2021). Colorectal cancer (CRC) affected approximately 2 million persons worldwide in 2020 (Sung et al., 2021). Cancer incidence is rapidly growing due to complex causes, most importantly because of the greying of the population and changes in the prevalence of risk factors (Sung et al., 2021). CRC is the third most common malignant disease after lung and breast/prostate cancer, accounting for 9.2% of all cancer-related deaths worldwide in 2020.

Approximately 40% of patients diagnosed with CRC in Norway were ≥80 years old (Cancer Registry of Norway, 2022). However, national guidelines in Norway do not recommend the systematic surveillance of patients aged ≥80 years for recurrent disease, and the postsurgical care of patients ≥80 years old after curative CRC surgery is provided by the general practitioner (GP) according to the individual patient’s needs and wishes (The Norwegian Directorate of Health, 2021). This results in limited knowledge about the recovery process among patients ≥80 years old. This gap in knowledge concerning the impact of psychosocial and physical factors on recovery, everyday life, challenges encountered, and potential unmet needs has the potential to impose a burden on the healthcare system by allowing problems in persons ≥80 years old to develop instead of focusing on facilitation and prevention (Shapiro, 2018). Further knowledge of the older patient’s recovery, in both the short- and the long-term, is essential to optimize postoperative follow-up care. It is important for healthcare personnel in contact with older patients treated for CRC to be aware of the challenges the older persons may encounter in recovery to be able to assist when and where needed and promote their coping capacity.

2 Background

This thesis explores short- and long-term recovery among persons ≥80 years old following curative surgery for CRC. Investigating the person's perspective on recovery and the associated factors will result in new knowledge of importance to provide older patients with quality follow-up care after curative CRC surgery.

2.1 Colorectal cancer

In 2019, 4499 persons were diagnosed with CRC in Norway, and it is estimated that 6000 persons will be diagnosed annually by 2030 (The Norwegian Directorate of Health, 2021). The overall survival rate has increased over the last decades, especially among older patients (Bos et al., 2019). In 2019, 295 855 persons in Norway were living beyond cancer treatment, 4668 of whom were ≥80 years old and diagnosed within 4 years (The Norwegian Directorate of Health, 2020). With an increasing number of patients living beyond cancer treatment, researchers seem to have expanded their focus to include recovery.

2.1.1 Colorectal cancer diagnosis, treatment and staging

CRC is a fatal disease if left untreated, leading to serious complications and suffering. The use of different examination techniques such as endoscopy, computed tomography and magnetic resonance imaging, as well as histopathology and tumour markers, is essential for establishing the diagnosis and staging of the disease (The Norwegian Directorate of Health, 2021).

In this context, a nurse navigator is the nexus to healthcare services for patients. The nurse navigator arranges appointments for different examinations, provides relevant information about the procedure and is the contact person should questions arise during the diagnostic process.

Treatment options are elaborated on by a multi-disciplinary team consisting of relevant medical professionals based on the diagnostic work-up and according to national guidelines for the treatment for cancer in the colon and rectum (The Norwegian Directorate of Health, 2021). These recommendations form the basis of final treatment decisions and informed consent.

Radical resection of the tumour, that is, the affected bowel segment with central vascularisation and lymph nodes, remains the cornerstone for curative CRC (stages I–III) treatment. Elective surgery is considered safe for all patients, including persons ≥80 years of age (Bagnall et al., 2014; Forsmo et al., 2017). In some instances, multimodal treatment may be recommended (The Norwegian Directorate of Health, 2021). Additionally, surgery may sometimes involve the creation of either a temporary or a permanent stoma (Anaya et al., 2011; Rønning et al., 2016). In Norwegian hospitals, 'enhanced recovery after surgery' (ERAS) protocols, also referred to as fast-track programs, are implemented to optimize the quality of surgical treatment for CRC (Ljungqvist et al., 2017). ERAS uses multimodal care, such as early physical activity and nutritional input after surgery. A systematic review on CRC patients over 65 years of age found ERAS protocols to shorten the length of stay in the hospital and decrease complications after CRC treatment (Bagnall et al., 2014). Fast-track programs in the hospital may result in early discharge, and subsequently, postoperative recovery continues in the patients' home municipality without the bedside presence of specialised nurses and surgeons. Therefore, municipality healthcare such as homecare nursing and nursing homes are considered to play a central role in early recovery in some cases.

After surgery, the removed bowel specimen is subject to histopathologic examination to stage the cancer. The staging is based on tumour-node-metastasis (TNM), encompassing the assessment of local growth (T), lymph node metastasis (N) and metastasis to other organs (M) (The Norwegian Directorate of Health, 2021).

2.1.2 Colorectal cancer among older persons

Previous research shows that mortality rates during the first year after CRC surgery are significantly higher in patients ≥80 years old than in younger patients (Dekker et al., 2011). In recent years, the difference in survival between old and young patients had decreased somewhat but still exists (Breugom et al., 2018). However, older persons who survived the first year after surgery had a similar 5-year conditional relative survival (i.e., mortality related to the disease and its treatment given survival during the first year after treatment) to that of younger patients (Bos et al., 2019).

It is estimated that the prevalence of older persons will rise in the coming years. Simultaneously, the number of patients surviving CRC treatment will grow. A person's numeric age does not necessarily reflect their biological age. Older patients 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 (Aldwin et al., 2017; Hinz et al., 2014; Kirkevold et al., 2014). Consequently, older patients with cancer constitute a heterogeneous group, varying from individuals in good health to individuals with increased vulnerability to cancer treatment (Aldwin et al., 2017).

Old age is also referred to as an age with an accumulation of losses (Pitt, 1998), including losses due to an adjustment to altered roles in society, loss of bodily function and cognition, and disruption of social network through the loss of spouse, siblings and peers (Pitt, 1998). This variety of losses might occur at an accelerated pace when reaching an older age, either suddenly or gradually (Balducci & Extermann, 2000). To compensate for the many losses and reduced capacity that older patients might experience, social support can be a vital resource (Jatoi et al., 2016).

2.1.3 Recovery from colorectal cancer among older persons

This thesis defines recovery as a process of ‘returning to normal compared to the preoperative standard of physical, social and psychological well-being’ as per Allvin et al. (2007) and Zalon (2004). A qualitative study exploring patients’ understanding of the recovery process found that patients considered recovery after abdominal surgery to end when symptoms disappeared and the participant could return to normal habits and routines, regain independence, enjoy life and overcome the mental strain from the diagnosis, treatment and the process itself (Rajabiyazdi et al., 2021) .

Because of the advances in awareness, diagnosis and treatment options, more patients will live with their cancer diagnosis as a chronic illness. However, older patients are more prone to having delayed recovery compared to younger patients (Manceau et al., 2012). It cannot be taken for granted that younger and older patients treated for CRC have the same needs in recovery; thus, they should be studied separately. Older patients are vulnerable to age-related changes in addition to experiencing more symptom distress in recovery (Aziz, 2007), potentially affecting recovery and coping ability in daily life.

2.1.4 Physical factors in recovery among older persons

Recovery can be influenced by different physical factors such as bodily decline, cancer recurrence and secondary malignancy in addition to disturbing complications and symptoms of a passing or permanent nature (Aziz, 2007; Hewitt et al., 2005; Pezaro & Jefford, 2009; Rønning et al., 2016). Eighty-two per cent of older frail patients experience postoperative complications (Ommundsen et al., 2018). The most common complications are anastomosis leakage, septicaemia and delirium (Fagard et al., 2017; Samuelsson et al., 2019). In 19% of older frail CRC patients, complications were registered to occur after discharge. The most common complications were either urinary tract infection or surgical site infection, representing an extra burden in recovery (Fagard et al., 2017; Ommundsen et al., 2018) that required the older person to seek medical attention, often resulting in additional obstacles such as wound care, which could potentially affect the ability to cope during recovery.

Furthermore, half of older CRC patients experience a decline in physical functioning after treatment (van Abbema et al., 2017). Older patients recovering from CRC surgery report a lack of individualisation in rehabilitation when returning home from the hospital (Samuelsson et al., 2018). Nearly half of older patients were in need of care after discharge from the hospital (Li et al., 2015). Two years after CRC surgery, older persons still reported a significant decline in physical functioning (Couwenberg et al., 2018; Rønning et al., 2014). This functional decline may lead to lower functional levels and thus accelerate the aging process and increase the risk of disease (Kirkevold et al., 2014). Thus, reduced physical function and symptom burden have a negative effect on recovery, everyday life and coping capacity (O'Gorman et al., 2018; Rønning et al., 2014).

Knowledge of older persons' experiences with recovery after CRC surgery may be a prerequisite to identify challenging areas in recovery after discharge. This knowledge could be essential for facilitating optimal recovery. So far, there is little detailed knowledge on older patients' course of development after discharge from the hospital concerning recovery, rehabilitation and daily life.

2.1.5 Psychosocial aspects of colorectal cancer recovery among older persons

Current state-of-the-art cancer care provides medical treatment that ensures a higher overall survival among all patients. However, cancer care frequently fails to consider the psychosocial aspects of the disease, which are important aspects beyond surgical factors that can be particularly important in the recovery of older CRC patients (Page & Adler, 2008). Recovery from surgical cancer treatment goes beyond a physical process as it is also affected by psychosocial aspects of the recovering person's life, such as emotions, behaviours and social relationships (Page & Adler, 2008). Already in 1994, a study of patients living beyond CRC treatment found psychosocial problems to significantly affect the rehabilitation process (Schag et al., 1994). A successful curative cancer surgery does not exclude psychosocial or physical problems related to the cancer diagnosis and its treatment (Aaronson et al., 2014).

Approximately half of older CRC patients are in need of support following discharge from the hospital (Li et al., 2015). A study encompassing several cancer diagnoses found that patients of all ages diagnosed with CRC perceived lower social support than those with any other cancer (Eom et al., 2013). Another study of CRC patients of all ages revealed that being older, being female, having comorbidities and a diagnosis of rectal cancer characterized the patients most prone to having lower and declining levels of social support (Haviland et al., 2017). The same study found perceived social support levels to have declined 2 years after treatment. However, health-related quality of life was found to have improved already 3 months after surgery and sustained forward compared with preoperative levels (Rønning et al., 2016; van Heinsbergen et al., 2019).

Psychosocial problems can cause additional suffering during recovery, in addition to weakening adherence to health-promoting activities, and prevent individuals from receiving needed healthcare and managing recovery (Page & Adler, 2008). Older patients recovering from CRC surgery express unmet support needs (Samuelsson et al., 2018; Williams et al., 2019). Unmet psychosocial needs can negatively affect a persons' coping ability and ability to access and receive necessary healthcare resources, thus affecting their ability to manage recovery (Page & Adler, 2008). There is little detailed knowledge on older persons recovering from curative CRC treatment in terms of their experience of continuity of care, support and coping capacity and the impact this has on recovery in their everyday life.

2.1.6 Coping capacity in older patients with cancer

Receiving a cancer diagnosis, undergoing cancer treatment, and subsequently returning to the desired level of health can be an extremely stressful experience (Page & Adler, 2008). The effectiveness of healthcare and the older person's ability to cope during recovery can be compromised by a failure to consider and address psychosocial problems. Coping refers to the capacity of individuals to face stressful situations and manage to overcome them (Folkman & Moskowitz, 2004). In relation to understanding the contribution of coping capacity to outcomes in cancer recovery, the concept of sense of coherence (SOC) has attracted attention (Kenne Sarenmalm et al., 2014; Sarenmalm et al., 2013a). SOC can be seen as an individual's orientation and understanding of the world and as a health-promoting resource that measures a person's capacity to cope (Antonovsky, 1979). Research has shown that a greater SOC protects against negative health outcomes in an older general population (Boeckxstaens et al., 2016).

While there is a gap in research on the role of the SOC in CRC recovery among older persons, existing research with cancer patients of this age group indicates that SOC affects both the perception and management of recovery. Older patients with breast cancer with a lower SOC experienced more symptoms and a higher degree of symptom burden

(Kenne Sarenmalm et al., 2014). SOC was also a significant predictor of the number of coping strategies utilized by older patients with cancer to manage stressful events (Sarenmalm et al., 2013b). A high SOC positively correlated with coping strategies such as the use of distraction, situation redefinition, direct action, acceptance and relaxation. On the other hand, a low SOC correlated with coping strategies such as seeking social support and religion (Sarenmalm et al., 2013a). A significant positive correlation was seen between SOC and quality of life, that is, the better the SOC, the more enhanced the perception of quality of life among older patients with cancer (Sarenmalm et al., 2013b).

By exploring factors in CRC recovery correlating with SOC, one may better understand how follow-up care and recovery can be optimized and identify areas of CRC recovery among the old with potential for improvement. It seems to be important to recognize that recovery is affected by psychosocial factors to optimize older persons' ability to cope with challenges in recovery.

2.2 The Norwegian healthcare system in relation to colorectal cancer treatment

The principle of a welfare state forms the foundation of the Norwegian public healthcare system, entailing equal access to medical services for all citizens regardless of social and/or economic status or geographic location. Cancer treatment is free of charge and available to all Norwegian citizens, financed through the state budget.

2.2.1 The Norwegian healthcare system is two-pronged

The Norwegian healthcare system is two-pronged: the state is responsible for specialist healthcare, while the municipalities are responsible for primary healthcare (Norlyk & Harder, 2011; Romøren et al., 2011). Regarding the CRC treatment trajectory, specialist healthcare services provide diagnosis and treatment in hospitals or outpatient clinics. To improve the utilization of the available healthcare resources in Norway, the Coordination reform has facilitated the transition of patients from hospitals to primary healthcare services once the specialized treatment is completed (Norlyk & Harder, 2011; Romøren et al., 2011). Thus, a greater part of the recovery process takes place after discharge from the hospital to primary healthcare services (Ljungqvist et al., 2017).

GPs are primarily responsible for the patient's CRC trajectory in primary care services (Norlyk & Harder, 2011; Romøren et al., 2011). The GP executes a systematic follow-up program after treatment for cure according to national recommendations. They are also responsible for assisting the patients in recovery (The Norwegian Directorate of Health, 2021). After discharge from the hospital, primary healthcare is responsible for the patients' healthcare needs, including stays in a nursing home or homecare nursing, as required by the individual patient (Devon et al., 2011; Li et al., 2015; Romøren et al., 2011).

The transition from hospital to home can itself sometimes be a challenge for older patients. The process can lead to insecurity because of a lack of information. The abrupt change in focus after discharge from the hospital and between different levels of healthcare services can cause uncertainty for the older person: while hospital care mainly focuses on medical treatment, the focus at home or in primary healthcare services is on self-management (Hvalvik, 2015).

Healthcare services often fall short in collaborating between different levels and thus reduce the perceived continuity of care for the older patient (Le Berre et al., 2017). This was confirmed in a Swedish study in which older CRC patients were confused about which part of the healthcare service that was responsible for their follow-up care after surgery (Samuelsson et al., 2018). A literature review found that both cancer patients and GPs supported that GPs should have a greater role in follow-up cancer care after discharge (Meiklejohn et al., 2016). Furthermore, GPs could be difficult to reach and have a heavy workload with frequent replacement, making it difficult to form a doctor-patient relationship. However, homecare services are expected to be a link between the older patient and their GP, thus addressing the lack of continuity of care (Nilsen et al., 2022). Nevertheless, not all older patients need help from these services in their home municipalities after discharge as they may manage on their own.

2.2.2 Follow-up care for colorectal cancer patients in Norway

In Norway, a systematic follow-up program to detect recurrence is recommended for all patients up to 80 years of age after surgical treatment for CRC with curative intent, that is, for disease stages I–III. The main criterion for entering the systematic follow-up program is the assessment that the patient can undergo extensive surgical or oncological treatment. Consequently, the standard post-surgical care regimen for patients ≥80 years after curative CRC surgery is determined individually outside systematic follow-up programs, which results in a lack of a standard of care for older patients (The Norwegian Directorate of Health, 2021).

In 2021, the guidelines changed to focus on good information for patients and their next of kin in addition to discovering and treating symptoms and functional impairment related to cancer treatment (The Norwegian Directorate of Health, 2021).

2.3 Overall research aim and objectives

The overall aim of this study was to investigate the psychosocial and physical factors that are important for recovery after curative CRC surgery among persons ≥80 years of age.

To achieve the overall aim of the project, three studies were designed with the following aims:

- To explore the experiences of individuals aged ≥80 years recovering from surgery for colorectal cancer and the challenges they may encounter after discharge from hospital (Paper I)
- To explore the associations between sense of coherence, perceived social support, and demographic and clinical characteristics among survivors ≥ 80 years treated for curable colorectal cancer. To 1) explore associations between SOC and demographic variables (gender, age, marital status, and living situation) and clinical variables (recipient of homecare nursing, functional status, cancer site, severe postoperative complications, and readmissions), 2) explore perceived social support in association with demographic and clinical variables, and 3) test the hypothesis that high levels of perceived social support correlate with a high SOC score (Paper II)
- To explore the experience of persons ≥80 years of age during recovery up to two years after curative colorectal cancer surgery (Paper III)

The papers are referred to by their Roman numerals in the text.

2.4 Outline of the thesis

The thesis comprises two parts, a general part (Part I) and three original papers (Part II).

Part I comprises eight chapters. **Chapters 1 and 2** consist of an extensive introduction to CRC among older individuals and the Norwegian healthcare system in relation to the CRC trajectory. **Chapter 3** presents the theoretical background of this thesis. **Chapter 4** describes the methodology with philosophical considerations, the research design, as well as the ethical considerations and research quality. The results are presented in **Chapter 5**. **Chapter 6** discusses the implications of the findings. **Chapter 7** summarizes the conclusions along with a presentation of implications for practise and future research, followed by a list of references in **Chapter 8**.

Part II consists of three original peer-reviewed research articles and the relevant appendices.

2.5 Articles included in the thesis

Three articles are included in the thesis:

Paper I

Eriksen, K. S., Husebø, S. I. E., Kørner, H., & Lode, K. (2021). Experiences of recovery from colorectal cancer surgery after hospital discharge among the oldest old: A qualitative study. *Nordic Journal of Nursing Research*, *41*(3), 140-148.

Paper II

Eriksen, K. S., Lode, K., Husebø, S. I. E., & Kørner, H. (2022). Exploring variables affecting sense of coherence and social support in recovery after colorectal cancer surgery among the oldest old. *Geriatric Nursing*, *47*, 81-86.

Paper III

Eriksen, K. S., Husebø, S. I. E., Kørner, H., & Lode, K. (2023) Long-term recovery after colorectal cancer surgery among the old: an interview study. Accepted for publication in *Cancer Nursing.*

3 Theoretical background

The theoretical background of this thesis and a central part of the related psychosocial factors are based on the health-promoting theory ‘salutogenesis’, with a particular focus on the concept of ‘sense of coherence’ (SOC). This theory can inform the understanding of the complex situation experienced by older persons in recovery after CRC surgery. By applying a health-promoting perspective such as SOC, the theory and concept can shed light on different aspects of importance in how patients stay healthy despite experiencing adversity and further describe a person’s capacity to respond to stressful situations (Eriksson, 2017). The theory of salutogenesis is presented briefly below, followed by a description of the concept of SOC and the health-promoting resource of social support.

3.1 Salutogenesis

In the 1970s, Antonovsky developed a health promotion theory termed salutogenesis that stimulated a shift in focus from studying factors causing illness to including factors that promote health (Antonovsky, 1987, 2012). Instead of viewing health and illness as contradictory, Antonovsky perceived health and illness to be at different ends of a continuum (Erikssson & Lindström, 2015). When exposed to a stressful situation, action must be taken to manage the stress; this action can have a pathological, neutral or health-promoting outcome. The outcome of the action affects its placement on the continuum, depending on the adequate management of the stress (Antonovsky, 2012). In this thesis, salutogenesis was used to inform and recognize older persons’ ability to engage resources, mechanisms and strategies for coping. Furthermore, the theory helped identify resources that generate, maintain and improve health in older participants (Antonovsky, 2012; Lindström, 2018), also referred to as the person’s SOC.

3.1.1 Sense of coherence

SOC is defined as

> '… a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that one's internal and external environments are predictable and that there is a high probability that things will work out as well as can reasonably be expected' (Antonovsky, 1979, p. 123).

SOC contains three elements: comprehensibility, manageability and meaningfulness (Antonovsky, 1979; Eriksson, 2017). Comprehensibility refers to the extent of the individual's ability to understand and make sense of a stressful situation. A high degree of comprehensibility makes individuals less likely to experience unanticipated situations and complications as chaotic and confusing (Haugan & Rannestad, 2014). Comprehensibility constitutes the cognitive component in SOC (Eriksson, 2017; Haugan & Rannestad, 2014).

Manageability refers to the ability to determine the availability of the necessary resources to meet the demands of the situation, as well as to apply cognitive processes to establish an appropriate method to strategically use the resources (Antonovsky, 2012). In this thesis, manageability represents the extent to which older persons feel competent in managing the stressful situations experienced in recovery (Antonovsky, 2012; Haugan & Rannestad, 2014). To manage stressful situations, older persons depend on having the necessary resources at their disposal or in their external environment (Haugan & Rannestad, 2014). Manageability constitutes the behavioural component of SOC (Haugan & Rannestad, 2014). A person possessing a high degree of manageability will not view themselves as victimized by the cancer, treatment and other challenges experienced in recovery but rather view situations as challenges that are a part of life and that they are capable of handling (Antonovsky, 2012). In contrast, a person with a low SOC views challenges as threats or views life as unfair (Antonovsky, 2012).

Meaningfulness describes the ability of the older person in recovery to perceive the investment of energy and resources as worthwhile when engaging with the challenging situations they face during recovery (Antonovsky, 1987; Haugan & Rannestad, 2014). The challenge they face must be meaningful emotionally and not just cognitively. Meaningfulness is the motivational component of SOC (Haugan & Rannestad, 2014). According to Antonovsky, finding meaning in the situation does not involve giving meaning to every aspect of life but rather focusing on the positive aspects of life, regardless of their origin. This ascribed meaning will provide the motivation and energy required to view the cancer as a challenge worth fighting to overcome (Antonovsky, 2012; Haugan & Rannestad, 2014). However, a person with a low degree of meaningfulness can feel overwhelmed and lose hope about overcoming the cancer and recovering (Antonovsky, 2012).

The stronger the individual's SOC, the more capable they will be of engaging resources to cope with challenging situations. These resources comprise material resources, such as money and safe living conditions, and non-material resources such as intelligence, social support, coping strategies, cultural stability, preventive health orientation, and health status (Haugan & Rannestad, 2014; Horsburgh & Ferguson, 2012; Idan et al., 2017). For persons with a low SOC, a constant deficit of resources will create an impression of stressful situations being chaotic and incomprehensible. In contrast, a person with a high SOC, upon encountering a situation characterized by resource deficits, will seek out former experiences that can counteract the stressful situation (Antonovsky, 2012).

A stressful life event such as receiving a cancer diagnosis and undergoing the required treatment can alter an individual's SOC, even late in life (Antonovsky, 2012; Nilsson et al., 2003; Volanen et al., 2007). This is especially true for those with a moderate to low SOC. A deficiency in resources will affect SOC, which can lead to a downward spiral. Older persons generally tend to have gained coping strategies from dealing with prior stressful experiences, which influences them to appraise events as being less stressful compared to younger adults (Aldwin et al., 2017). The health-promoting potential of SOC has led Horsburgh and Ferguson (2012) and several others to promote the use of a SOC scale as a clinical indicator to identify persons who can benefit from education on coping strategies.

3.1.2 Social support as a resource

The benefits of social support have been studied in the context of recovery from cancer treatment among older persons as well as persons recovering from CRC treatment.

In a stressful situation, perceived social support is seen to strengthen a person's SOC (Antonovsky, 1987; Drageset et al., 2014). Social support comprises a network of persons who can assist during illness (Sjolander & Ahlstrom, 2012). Support may come from different actors such as partner, family, friends or persons in the community (Taylor, 2011). Social support can be understood as the degree a person's basic social needs are met through their social network (Ahmad et al., 2013). Social support in older individuals with cancer is shown to be a resource that has a direct effect on physical health, emotional adjustment, well-being and survival (Kadambi et al., 2020). Social support is a key resource for older cancer patients in terms of mitigating the negative effects of cancer treatment and improving cancer outcomes, health, emotional well-being and quality of life (Cohen, 2004; Haviland et al., 2017; Kadambi et al., 2020). Informal caregivers, family and close friends represent the main sources of support for older individuals with cancer. Support from family and friends likely enables older individuals to receive timely follow-up care after cancer treatment, attend medical appointments and receive emotional support (Jatoi et al., 2016).

When assessing social support, a distinction is made between perceived social support and received social support. Received social support refers to the quantity of support received and supporters available (Eagle et al., 2019). However, interpersonal contact does not necessarily correlate with support. Perceived social support concerns the cognitive appraisal of the availability and adequacy of support (Eagle et al., 2019). Perceived social support reveals an interpersonal relationship's ability to serve particular functions. Perceived social support can be divided into five categories: affectionate, tangible, informational, emotional and social companionship. Affectionate support entails the expression of love and affection. Tangible support, also referred to as instrumental support, involves material aid or behavioural assistance. Informational support comprises advice or guidance that can be helpful in problem-solving. Emotional support consists of the expression of empathy, understanding and positive affect. Social companionship includes leisure activities or recreational activities (Sherbourne & Stewart, 1991).

Because older persons are generally exposed to the risk of social, functional and cognitive decline, the demands of cancer treatment and recovery can be experienced as especially difficult (Aldwin et al., 2017; Hewitt et al., 2003; Kirkevold & Brodtkorb, 2014). Therefore, older patients in cancer recovery are more likely to experience social support needs of both a physical and a nature, which can limit their ability to cope (Robb et al., 2013). Correspondingly, social support can aid older persons in navigating challenges and emotional reactions during cancer recovery (Langford et al., 1997).

4 Methodology

This chapter presents the mixed methods research performed in this thesis. The chapter begins with a description of underlying philosophical considerations, followed by a description of the thesis research design and the individual studies therein. The chapter also provides details on the integrity of the research and ethical considerations related to the thesis.

4.1 Philosophical considerations

Nursing science has a tradition of adhering to the philosophical traditions of positivism, often used in quantitative research, or interpretivism, often used in qualitative research. Positivism is concerned with the empirical observation of reality, independent of human experience (Polit & Beck, 2008). In contrast, interpretivism is concerned with the human experience and sees reality as socially constructed (Blaikie & Priest, 2019). The natural relationship between these two paradigms represents an either-or stance (Johnson & Onwuegbuzie, 2004).

An alternative philosophical tradition needed to overcome this duality is pragmatism. Pragmatism is an action- and solution-oriented paradigm focusing on the research question and its consequences on the research (Yvonne Feilzer, 2010). There is a shift from an epistemological focus towards a methodological focus. Pragmatism therefore advocates the use of multiple methodologies and methods determined by the nature of the research question. Pragmatism promotes epistemological and methodological pluralism to obtain the required answers in research (Johnson & Onwuegbuzie, 2004).

This project is embedded within pragmatism. To achieve the overall aim, the incorporation of both qualitative and quantitative methods was deemed necessary. By combining the two methods, the project explores the complex phenomenon of recovery following curative CRC surgery among the oldest old in depth through a qualitative approach and coping capacity and social support through a quantitative approach applying statistical analysis (Creswell, 1999). This allows for additional insights into the experience of older persons after surgical treatment for CRC that would not have been revealed if only one method had been employed (Tashakkori & Creswell, 2007).

4.2 Research design

Mixed methods research combines and integrates qualitative and quantitative data to enhance the understanding of the phenomenon studied (Creswell & Clark, 2017; Ponterotto et al., 2013). The main purpose of applying a mixed-method research design in this thesis was to obtain new information in an under-researched area. This design involved an initial qualitative inductive approach which formed the basis for further explorations using both qualitative and quantitative methods (Greene et al., 1989). The results of the first qualitative study informed the theoretical approach applied in this thesis and the development of the subsequent studies.

Applying a mixed methods research design in this thesis facilitates the complementarity, expansion and triangulation of data between the different studies. Complementarity allows for the development of a fuller picture of the research issue through the application of two data collection methods. Expansion increases the scope of the research through several phases and methods. Triangulation provides insight into the same phenomenon through different methods (Greene et al., 1989).

Based on the thesis objective, a multiphase mixed methods design was applied; this design goes beyond the classic mixed methods designs, comprises more than two phases and allows for shifts between qualitative and quantitative methods as needed (Creswell & Clark, 2017). The thesis includes four separate phases of research conducted sequentially, where

Phases 1–3 comprise individual studies and their associated papers. Figure 1 presents an overview of the research design.

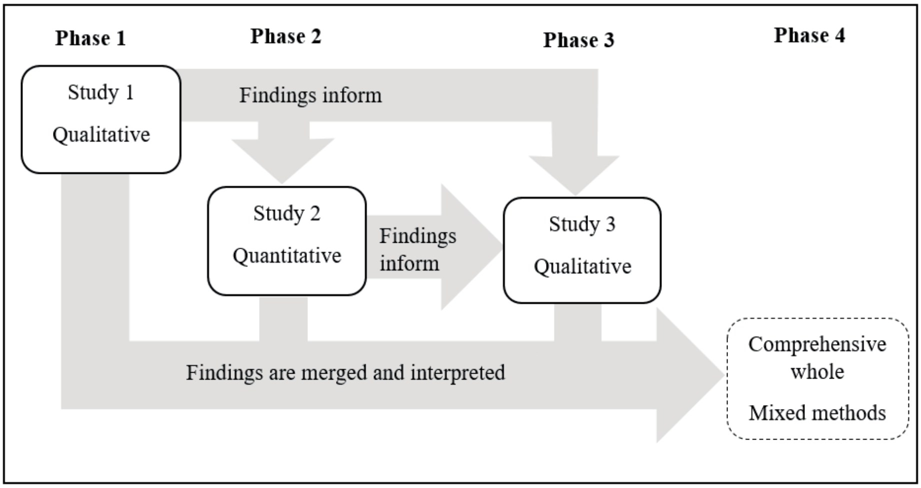


Figure 1 – Multiphase mixed method design inspired by Creswell and Clark (2017)

Phase 1 started with the identification of vulnerable areas in the everyday lives of older persons recovering from CRC surgery through a qualitative inductive interview study (Study 1, Paper I). The findings of Study 1 guided Phase 2 through the selection of the appropriate theory for the thesis and questionnaires for the survey in Study 2, resulting in Paper II. In Phase 3, the findings from Papers I and II informed the foundation of the interview guide utilized in Study 3 (Paper III). Finally, in Phase 4, the findings from Studies 1, 2 and 3 were merged within a matrix and interpreted to form a comprehensive whole (Plano Clark et al., 2010), presented in the results chapter of this thesis. The arrows in figure 1 represent points of interface. In this thesis, points of interface occur between the different phases, which are components of an iterative process in which former studies inform the subsequent studies with their results. Table 1 gives an overview of the aims and methods of the three studies in this thesis.

Table 1 – Overview of the three studies in this thesis

	Study 1	**Study 2**	**Study 3**
Aim	To explore the experiences of individuals ≥80 years recovering from surgery for colorectal cancer and the challenges they may encounter after discharge from hospital	To explore the associations between SOC, perceived social support, and demographic and clinical characteristics among survivors ≥80 years treated for curable colorectal cancer. To 1) explore associations between SOC and demographic variables (gender, age, marital status, and living situation) and clinical variables (recipient of homecare nursing, functional status, cancer site, severe postoperative complications, and readmissions), 2) explore perceived social support in association with demographic and clinical variables, and 3) test the hypothesis that high levels of perceived social support correlate with a high SOC score	To explore how patients ≥80 years of age experienced recovery up to two years after curative surgery for colorectal cancer
Design	Exploratory qualitative	Quantitative exploratory cross-sectional survey	Exploratory qualitative
Sample	10 participants	56 participants	18 participants
Data collection	In-depth interviews	Survey with the two questionnaires Sense of Coherence Scale (SOC-13) and Medical Outcomes Study-Social Support Survey (MOS-SSS). Additional clinical information was retrieved from patient records	In-depth interviews
Data analysis	Thematic analysis	Non-parametric statistical methods	Content analysis

4.3 Study context

The study took place in a university hospital in western Norway, the only institution offering healthcare and surgical services for a catchment area of 18 municipalities comprising rural and urban cities with a total of approximately 370,000 inhabitants. The Department of Gastrointestinal Surgery performs more than 300 elective or acute CRC operations annually, approximately 40% of which are on persons aged ≥80 years.

4.4 Phase 1: Qualitative, Study 1

To gain an in-depth understanding of the experiences of older persons returning home after CRC surgery and the possible challenges they face during this process, an exploratory qualitative study was performed. This phase laid the foundation for the thesis through Study 1. Findings from Study 1 are presented in Paper I. The results of this study informed the next phases with respect to theories utilized in the thesis and the design of the subsequent studies.

4.4.1 Recruitment and participants

Purposive sampling was applied to facilitate maximum variation between the participants regarding the type of cancer, functional status and gender to gain rich and varying descriptions (Patton, 2002). The inclusion criteria were the following:

- Treated electively with curative resections for CRC (stages I–III)
- ≥80 years of age
- Able to speak and read Norwegian

The exclusion criteria were as follows:

- Cognitive impairment
- Inability to speak and read Norwegian

Originally, 12 participants were recruited, but the medical condition of two participants prevented their participation. One interview was postponed by a few weeks due to declining health. As saturation was believed to have been achieved, recruitment was stopped, resulting in a sample of 10 participants further described in Table 2.

Table 2 – Characteristics of the participants in Study 1

Characteristics	***n***
Age	
Median (range)	82 (80–85)
Gender	
Female	5
Male	5
Marital status	
Married	4
Single/widowed/divorced	6
Children	
Yes	9
No	1
Location of cancer	
Colon	7
Rectum	3
Mobility aid preoperatively	
Yes	2
No	8
Creation of a stoma	4
Weeks from surgery to interview	5

Abbreviations: *n*, number

Participants were recruited from a gastrointestinal surgical ward in a hospital in western Norway. A nurse with no affiliation to the study approached eligible individuals regarding participation in the study. If consent was obtained, the person’s contact information was conveyed to the researcher. A date and time for the interview were set for 1 month later at the convenience of the participants. One week before the interview, the researcher called to confirm the appointment and rearranged the interview if needed.

4.4.2 Data collection

In-depth interviews were conducted between January and March 2016. The interviews took place in the participants' homes to inconvenience the older participants as little as possible. An interview guide was developed by the authors based on the research objective and relevant previous research (Beech et al., 2012; Browne et al., 2011; Jorgensen et al., 2012); see Appendix 1. The interview started with the question 'How did you experience coming home from the hospital?' Follow-up questions were asked to gain a deeper understanding of statements made by the participants. The interviews took place 1–2 months after surgery and lasted from 48 to 80 minutes.

4.4.3 Data analysis

Since the results of this paper would inform the subsequent studies, it was important for the analysis chosen for Study 1 to provide an accurate and applicable thematic reflection of the data as a whole without examination of the underlying ideas and assumptions in the data. Therefore, the thematic analysis by Braun and Clarke (2006) was chosen for the study. An inductive approach was applied to the analysis since the themes were required to be strongly linked to the data rather than being affected by a pre-existing coding frame. The analysis was performed at a semantic level and comprised a description and interpretation of the data through the formation of themes (Braun & Clarke, 2006).

A research team consisting of the PhD candidate (myself), main supervisor and co-supervisor conducted the analysis. For each new phase of the analysis, a team meeting was held to develop and maintain a shared understanding of the dataset and the analysis, after which I conducted the analysis accordingly. Data were organized and coded manually in a matrix using the Microsoft Word program.

The analysis entailed six phases: 1) familiarizing oneself with the dataset, 2) generating initial codes, 3) searching for themes, 4) reviewing themes, 5) defining and naming themes and 6) producing the report. However, thematic analysis is a nonlinear process in which one moves between the phases as needed. The present analysis alternated somewhat between phase 4 and 5 before the themes were perceived to present the story of the dataset as a whole.

4.5 Phase 2: Quantitative, Study 2

Phase 2 and Study 2 were based on the results of Study 1. To gain a broader understanding of the results of Study 1, a cross-sectional study design was chosen. The findings from Study 1 guided the selection of appropriate objectives, theory and accompanying measurements for the current study. By combining objective measurable data and clinical and demographic data with psychosocial data, such as perceived social support and coping capacity, possible associations and outcomes in long-term recovery might be determined. The results of this study are presented in Paper II.

4.5.1 Recruitment and participants

Participants were recruited from a hospital in western Norway. The inclusion criteria were as follows:

- Patients who underwent elective or emergency treatment for curable CRC (stages I–III) between 1 and 5 years prior to recruitment
- age ≥80 years at the time of the surgery

The exclusion criteria were as follows:

- Presence of cognitive impairment
- Inability to understand and read Norwegian

Since there is no standardized contact between eligible individuals and specialist healthcare services during long-term recovery for patients aged ≥80 years, a search of an administrative hospital database was performed to identify eligible participants.

To avoid pressuring the eligible persons to participate in the study, invitations to participate were sent by mail with information about the study, a questionnaire, a consent form and a stamped return envelope for the consent form. Once the consent form was received, the researcher called the participants to make an appointment for data collection through a guided telephonic interview based on the questionnaire; see Appendix 2. A guided telephonic interview format was chosen to ease the burden of participation in the study. Data were collected from patient records following the interview. However, some participants sent the survey back without a consent form, and consequently, data from hospital records are lacking in these cases. After 3 months, a reminder regarding the study were sent by mail to non-responders.

Ten participants neglected to return the consent form with the questionnaire; however, the questionnaires were included in the analysis as the returning of the questionnaire was seen as a deliberate action to participate. One participant was excluded since he was unable to return the questionnaire by mail or give an interview of the questionnaire by phone.

Of the 120 individuals invited to participate in the study, 56 consented, constituting a response rate of 47% (see the flow chart in Figure 2 for details). Table 3 gives a more detailed description of the sample.

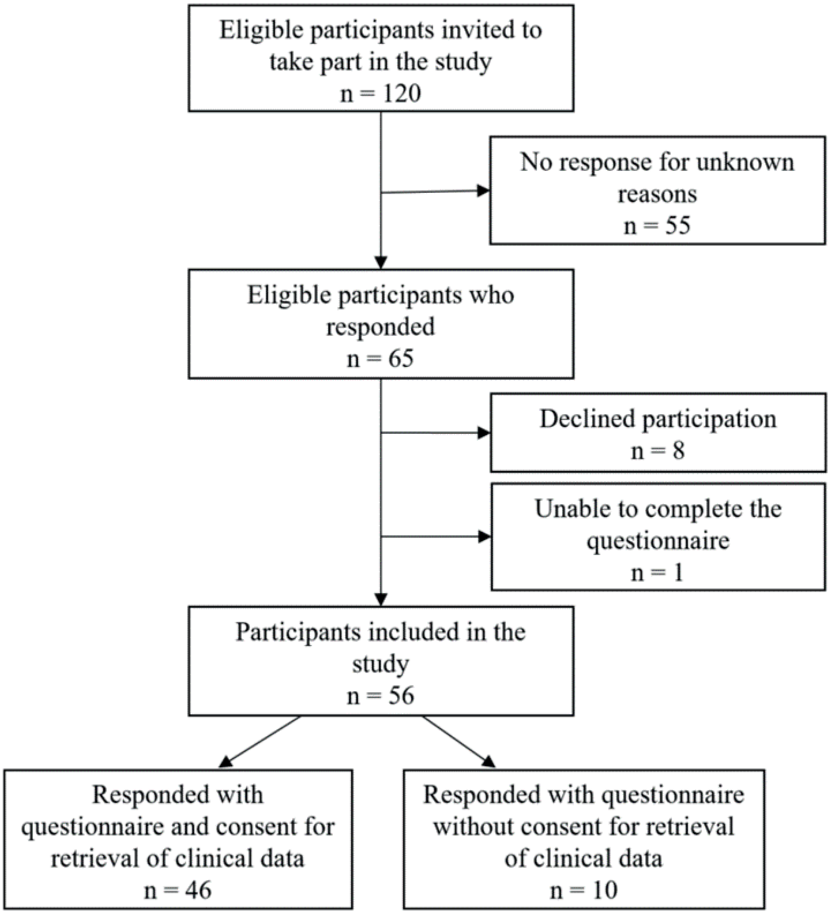


Figure 2 – Flowchart depicting the inclusion process for Study 2

Table 3 – Characteristics of the participants in Study 2

Characteristics		***n*** **(%)**	**Missing**
Gender	Male Female	17 (31.5) 37 (68.5)	2
Age group	80–86 87+	25 (54.3) 21 (45.7)	10
Marital status	Single/widowed Married/partners	34 (63.0) 20 (37.0)	2
Cohabiting		24 (44.4)	2
Current recipient of homecare nursing		18 (34.0)	3
ECOG	Grade 0 Grade 1 Grade 2 Grade 3	9 (16.7) 35 (64.8) 6 (11.1) 4 (7.4)	2
Comorbidity	Cardiovascular disease Respiratory disease	33 (71.7) 7 (15.2)	10
Cancer site	Colon Rectum	41 (89.1) 5 (10.9)	10
TNM	Stage 0 Stage I Stage II Stage III	1 (2.3) 12 (27.9) 16 (37.2) 14 (32.6)	13
ASA	2 3	21 (45.7) 25 (54.3)	10
Type of surgery	Right hemicolectomy Left hemicolectomy, sigmoid- or subtotal colectomy Rectal resection or amputations	28 (60.9) 12 (26.1) 6 (13.0)	10
Postoperative complications	Mild and moderate: Grade 1 and 2 Severe: Grade 3, 4, and 5	22 (47.8) 9 (19.5)	10
Readmissions		15 (32.6)	10
Presence of stoma	Never had a stoma Permanent stoma Temporary stoma, reversed	36 (78.3) 5 (10.9) 5 (10.9)	10

Abbreviations: *n*, number; ECOG, Eastern Cooperative Oncology Group performance status; TNM, tumour-node-metastasis classification; ASA, American Society of Anesthesiologists grading system.

Note: Three participants underwent surgery for B-cell lymphoma, a tubulo-villous adenoma and hyperplastic polyps and thus were not included in the TNM classification. Postsurgical complications were defined according to the Accordion Severity Classification of Postoperative Complications.

4.5.2 Measurements

Sense of coherence scale

To assess how a person handles stress and stays healthy, that is, the person’s capacity to cope, the sense of coherence scale (SOC-13) was applied. This questionnaire has 13 items divided into three domains: manageability (four items), comprehensibility (five items) and meaningfulness (four items). Originally, the SOC questionnaire contained 30 items; however, the condensed 13-item version is regarded to function as well as the full-length version (Eriksson & Lindström, 2005). The questions are ranked on a 7-point Likert scale with different endpoints for the various questions. A high score indicates a high SOC, with the total score ranging from 13 to 91 points (Eriksson & Mittelmark, 2017). Although Antonovsky discussed high and low SOC scores, no cut-off score for a high or low SOC was provided. Furthermore, Antonovsky recommended presenting the questionnaire in the form of one sum score and not as separate results for the three domains (Antonovsky, 1979). The SOC-13 revealed equivalent psychometric properties to those of the original questionnaire, with Cronbach`s α values ranging between 0.70 and 0.92 (Eriksson & Lindström, 2005). The SOC-13 has previously been used successfully in older Norwegian populations (Drageset et al., 2009; Drageset et al., 2012; Drageset et al., 2008; Eriksson & Lindström, 2005; Stensletten et al., 2016). The questionnaire has been translated into numerous languages and shows cross-cultural applicability, in addition to being validated and reliable (Eriksson & Lindström, 2005).

The Medical Outcomes Study-Social Support Survey

To measure how often various kinds of perceived support were available, the Medical Outcomes Study-Social Support Survey (MOS-SSS) was utilized (Sherbourne & Stewart, 1991). The questionnaire consists of 19 items that assess four domains: emotional/informational support (five items), tangible support (four items), affectionate support (three items) and positive social interaction (three items), with one additional item. The questions are ranked on a 5-point Likert-type scale where 1 is ‘None of the time’, 2 is ‘Occasionally’, 3 is ‘Some of the time’, 4 is ‘Most of the time’ and 5 is ‘All of the time’. The MOS-SSS displayed strong psychometric properties in the original study, with Cronbach`s $\alpha > 0.91$ (Sherbourne & Stewart, 1991). The questionnaire was translated to Norwegian by Nordtug et al. (2013). The MOS-SSS has been previously successfully utilized to study cancer patients, including CRC patients (Haviland et al., 2017; Sodergren et al., 2019; Williams et al., 2019).

Additionally, to assess the participants’ physical function, the Eastern Cooperative Oncology Group (ECOG) scale of performance status was used (Conill et al., 1990). To register the characteristics of each participant’s cancer, the pTNM (i.e., TNM based on pathological examination of the surgical specimen) (The Norwegian Directorate of Health, 2021) was obtained from their electronic medical records. Surgical postoperative complications were recorded according to the Accordion Severity Grading System (Strasberg et al., 2009).

4.5.3 Statistical analysis

Statistical analyses were conducted with IBM® SPSS® Statistics software v. 26. Data distribution, outliers and the presence of missing data were examined. Missing data on any variable were excluded from analysis when the variable was in analysis. Descriptive statistics were used to summarize the demographic and clinical characteristics of the sample. The chi-square test of independence was applied to explore differences between participants and non-participants. The Kolmogrov–Smirnow test revealed a non-normality of the data, and non-parametric tests were applied for the analysis of continuous variables. The Mann–Whitney U test was used to explore the relationships between the patients' reported outcomes and categorical demographic and clinical variables. Spearman's correlations were calculated to explore the bivariate relationship between SOC and MOS-SSS (and its subscales) and ranked demographic and clinical variables. Confounding variables were controlled for in the Spearman's correlation. Calculations of 95% confidence intervals (95% CIs) for Spearman`s correlation were based on a bootstrap method with 1000 samples. The correlation results were interpreted according to the work of Cohen, with a value below 0.29 being considered a small correlation, 0.30–0.49 a medium correlation, and above 0.5 a strong correlation (Cohen, 2013). A two-tailed p-value of less than 0.05 was regarded as statistically significant.

4.6 Phase 3: Qualitative, Study 3

Phase 3 and Study 3 build on the results of Studies 1 and 2, which informed the development of the interview guide. To gain a better understanding of the experience of older patients in long-term recovery and obtain in-depth descriptions of areas of interest from Study 2, a qualitative design was chosen. The results of this study are presented in Paper III.

4.6.1 Recruitment and participants

Recruitment was based on the following inclusion criteria:

- Patients who underwent curative CRC surgery (stages I–III) 1–2 years previously
- Age ≥80 years at the time of the surgery

The exclusion criteria were as follows:

- Presence of cognitive impairment
- Inability to speak and read Norwegian
- Persons treated less than 1 year ago or over 2 years ago

Eligible participants were supposed to be identified from the sample of Study 2. The inclusion and exclusion criteria were primarily the same as in Study 2, except that the time since surgery was shortened in the current study so that the participants would have a better recollection of events during recovery. However, because of the COVID-19 pandemic, data collection took place in two stages. First, participants were recruited from the sample of Study 2. An invitation to participate in the study was sent by mail with information about the study, a consent form and a stamped envelope for the return of the consent form. When the consent forms were obtained, the researcher contacted the participants to make an appointment for face-to-face interviews. However, data collection had to be paused because of increased COVID-19 incidence in the area. The pause in data collection resulted in the participants from Study 2 no longer matching the inclusion criteria as the time since their surgery exceeded 2 years. Therefore, a second screening of electronic patient records were conducted to identify eligible patients matching the inclusion criteria.

In total, 24 participants were recruited. However, some participants were excluded for a variety of reasons: three participants were excluded as they did not match the inclusion criteria. One interview was terminated by the researcher when it was discovered that the participant had impaired general health to the point where it was not appropriate to complete the interview. Finally, two participants were excluded as a result of saturation being achieved before the interviews were conducted. The remaining sample contained 18 participants, and a further description of the sample in presented in Table 4.

Table 4 – Characteristics of the participants in Study 3

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)

Abbreviations: *n*, number

4.6.2 Data collection

In-depth interviews were conducted between August 2020 and May 2021. Again, to create as small a burden as possible, the interviews were conducted in the participants' homes. An interview topic guide was developed (Appendix 3) based on the findings from Studies 1 and 2 in addition to previous research (Jakobsson et al., 2017; O'Gorman et al., 2018; Samuelsson et al., 2018). Follow-up questions were asked to clarify uncertainties and obtain more details about statements made by the participants. The interviews lasted approximately 1.5 hours.

4.6.3 Data analysis

In this study, content analyses by Graneheim and Lundman (2004) were chosen to provide an interpretation of the underlying meaning of the researched phenomena through the formulation of latent themes (Schreier, 2012). This method allows for the analysis of the data on different levels during the analysis process, namely manifest and latent content (Graneheim & Lundman, 2004; Lindgren et al., 2020). Manifest content describes the visible and obvious components of the analysis. Latent content involves an interpretation of the underlying meaning of the data (Graneheim et al., 2017).

Also in this study, a research team consisting of the PhD candidate (myself), main supervisor and co-supervisor discussed the analysis through team meetings. Thereafter, the PhD candidate conducted the analysis in line with our shared understanding.

The analysis was performed in two stages. First a de-contextualisation of the data was performed by identifying meaning units that were abstracted and given a code, followed by a re-contextualisation through the formation of categories and themes. The analysis was performed on a manifest level up to the formation of categories, following which the analysis was elevated in interpretation to look for the latent meaning in the material through the construction of themes (Graneheim et al., 2017; Lindgren et al., 2020). Data were transcribed in Microsoft Word before being sorted and analysed using Nvivo software.

4.7 Phase 4: Mixed methods, comprehensive whole

In this multiphase mixed methods design, the three studies were conducted and analysed sequentially to best support follow-up action in the subsequent studies (Creswell & Clark, 2017), as previously described. The consecutive separate analyses created an initial understanding of the different study findings, while simultaneously allowing the comparison of the findings in the thesis to gain a more comprehensive picture of the recovery process (Greene et al., 1989). By triangulating different methods over a time period, comparing the results of the studies could provide new insights, a more complete picture and a new meaning of the recovery process among older persons (Greene et al., 1989).

The results of the studies (1–3) were merged in a side-by-side comparison to gain a more comprehensive understanding of the phenomena studied (Creswell & Clark, 2017). A summary table was created as a part of the merging with a description in the results chapter of this thesis. The merging strategy followed five steps: first, after the initial separate analyses of the studies (1–3), interesting differences and commonalities between the studies' findings, which would be fruitful to compare, were identified. Second, based on this identification, meaningful groupings were created, constituting themes in this mixed methods thesis. Third, all the data of interest from the findings of the each study suitable for the created groupings were included in a summary table. Fourth, data within a grouping were directly compared with each other and the theme within the summary table. Finally, the summary table with accompanying descriptions is presented in the results chapter of the thesis, with an interpretation of the findings presented in the discussion chapter.

4.8 Integrity of research

To ensure the trustworthiness of the research findings and the overall quality of the research, every study should be evaluated in relation to the procedure utilized to generate the findings (Polit & Beck, 2021). The concepts and procedures used to ensure trustworthiness in qualitative research differ from those of quantitative research (Graneheim & Lundman, 2004). In this thesis, several initiatives were taken throughout the project to ensure the quality of the research, adhering to the research approach used in the separate research studies. First, descriptions of how the qualitative research (Studies 1 and 3) was conducted to uphold trustworthiness and how reflexivity was applied are included. Second, an outline of the reliability and validity of the measurements used in Study 2 are provided.

4.8.1 Trustworthiness in qualitative research (Studies 1 and 3)

Trustworthiness in qualitative research is a key concept when assessing research quality and is evaluated based on the four criteria of credibility, dependability, confirmability and transferability (Creswell & Poth, 2016; Lincoln & Guba, 1985).

Credibility refers to the truthfulness of the interpretation of the dataset (Graneheim & Lundman, 2004; Polit & Beck, 2008). The papers contain several direct quotations from the interviews, enabling the reader to judge the validity of the themes and sub-themes.

Dependability refers to the consistency of the data over time and in different situations (Graneheim & Lundman, 2004; Polit & Beck, 2008). Data were collected through in-depth interviews that challenge dependability as they contain open-ended questions that encourage the use of follow-up questions, resulting in interviews that are difficult to duplicate. However, to correct this, all interviews were conducted by the PhD candidate. An interview guide helped navigate the interviews and ensured that the same topics were explored. Additionally, both papers (I and III) present an elaborate description of the methodology from recruitment to analysis, thereby enabling the reader to judge the dependability of the research process (Nowell et al., 2017). The Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist was applied for the reporting of Paper I (Tong et al., 2007).

Confirmability refers to the findings reflecting the participants' voices and not the researchers' prior understanding. This was ensured by conscious self-awareness and critical reflection throughout the study processes, further elaborated in the *Reflexivity* section of this chapter. Furthermore, three researchers performed the analysis together through team meetings, where different perspectives on the data and themes were discussed (Nowell et al., 2017).

Transferability refers to the ability to transfer the findings to a similar context or apply them to another group (Creswell & Poth, 2016; Polit & Beck, 2008). This was ensured in both studies by including rich descriptions of the participants and setting.

4.8.2 Reflexivity

Another concept important for maintaining quality, professional discretion and ethical practice in research is reflexivity (Fook, 1996; Taylor, 2000). Reflexivity is the continuous critical process of introspection that creates self-awareness of personal background, values and biases that could otherwise influence the research process and interpretation (Polit & Beck, 2021). Simply put, reflexivity is the process of acknowledging and reflecting on the researcher's role and the knowledge produced (Clarke & Braun, 2013). The PhD candidate played a dual role in this thesis as a researcher and nurse practitioner. The PhD candidate is employed at the surgical ward where the patients surgically treated for CRC recuperate after surgery. However, there was no prior relationship between the researcher and the participants.

Nevertheless, the experiences and perceptions of the researcher impart a unique understanding of the different aspects of recovery from surgery. Presenting myself as a researcher with knowledge from the clinic could create an opportunity for the participants to talk about issues that are difficult to discuss with persons without knowledge of the field. At the same time, this closeness to the field presents a threat of bias to objectivity in the analysis (Greene, 2014). To counteract this, team meetings were held throughout the analysis process to ensure a shared understanding of the dataset.

4.8.3 Reliability and validity (Study 2)

Reliability and validity are two core constructs when determining the quality of quantitative measurements. Their purpose is to ensure the accuracy of the results and aid in the evaluation of the research process (Mohajan, 2017).

Reliability refers to the consistency of the measurement, precision and repeatability of results, and absence of measurement errors (Mohajan, 2017; Polit & Beck, 2021). Indicators of established reliability include internal consistency, test-retest and inter-rater reliability (Kimberlin & Winterstein, 2008). Cronbach's α was applied to determine the internal consistency of the measurements in this study. The results range from 0.0 to 1.0, where 0.7 or higher is considered an acceptable reliability score (Heale & Twycross, 2015). The internal consistency in Study 2 was acceptable for both the SOC-13 and MOS-SSS as a whole and their sub-scales, with a Cronbach's $\alpha > 0.83$.

Validity is defined as the extent to which an instrument measures what it asserts and is designed to measure (Polit & Beck, 2021). However, unlike reliability, there are no equations to measure validity; validity is a property of inference and not a property of the test itself (Kimberlin & Winterstein, 2008; Polit & Beck, 2021). It refers to the approximate certainty of the truth of an inference (Lund, 2005). One aspect of validity relates to whether the instrument and statistical analysis are appropriate to achieve the research aim. In the cross-sectional study, the instrument consisted of questionnaires which had been previously successful with older cancer patients and had provided good psychometric properties. The questionnaires and statistical analysis are described in the materials and methods section of Study 2 in addition to this thesis. Furthermore, because of the observational nature of the cross-sectional study, no inference of causality could be made because of the lack of evidence between exposure and outcome. However, the observed correlations are described in Study 2.

4.9 Ethical considerations

This project was carried out in accordance with the ethical guidelines of the Declaration of Helsinki (World Medical Association, 2018). The studies were approved by the Regional Committees for Medical and Health Research Ethics (2015/1500, 2017/1739 and 19983) as well as the hospital (see Appendix 4).

The participants were informed both verbally and in writing of their rights during inclusion and again before data collection. They received information regarding the voluntary nature of the study and their right to withdraw from the study without any repercussions (see Appendices 5–7). In the quantitative study, information regarding the participants' rights was included in the letter describing the study. Written informed consent was obtained from the participants before data collection. It was emphasized that participation had no bearing on the treatment they received for their CRC and/or follow-up care.

The participants were also informed of data anonymity, data storage and security considerations. The security of data in all three studies was ensured through the separate storage of identifiable information and data on separate secure servers.

5 Results

In this section of the thesis the results from each study is presented separately, followed by the presentation of the merged findings in a summary table with an accompanying description.

5.1 Paper I

Experiences of recovery from colorectal cancer surgery after hospital discharge among the oldest old: a qualitative study

This study explored the experiences of persons aged ≥80 years recovering from surgery for CRC after discharge from the hospital.

The analysis identified two themes describing the recovery process and the challenges the patients encountered. The first theme, *Managing the recovery from CRC surgery,* discloses the participants' experiences of recovery from CRC surgery and the resources they used, conveyed through the sub-themes *Coping with the cancer diagnosis*, *CRC and treatment-related problems*, *Social network and healthcare services ameliorate transition from hospital to home* and *Stoma is an extra burden.*

The second theme, *Insufficient follow-up from healthcare services after CRC surgery,* illustrates the difficulties and challenges the older participants experienced when returning home from the hospital after curative CRC surgery with the sub-themes *Lack of information can make it more complicated to take care of oneself*, *The strain of follow-up care* and *Lack of continuity of care.*

The findings demonstrate that the follow-up care available for older patients treated for curative CRC is sub-optimal, and further developments are required. Meanwhile, it is important for healthcare personal in contact with this group of patients in both specialist and primary healthcare services to be aware of the challenges they encounter and facilitate individualised follow-up care.

5.2 Paper II

Exploring variables affecting sense of coherence and social support in recovery after colorectal cancer surgery among the oldest old

The second paper explored associations between sense of coherence, perceived social support, and demographic and clinical characteristics among survivors ≥80 years treated for curable CRC. Through 1) explore associations between SOC and demographic variables (gender, age, marital status, and living situation) and clinical variables (recipient of homecare nursing, function status, cancer site, severe postoperative complications, and readmissions), 2) explore perceived social support in association with demographic and clinical variables, and 3) test the hypothesis that high levels of perceived social support correlate with a high SOC score.

The results show that SOC is associated with age at surgery and physical function (ECOG). No associations were found between SOC and severe postoperative complications or readmissions. Women were found to report higher levels of perceived social support than men. In addition, current receipt of homecare nursing appeared to be associated with lower levels of *affectionate support* and *social interactions*. Participants experiencing readmission after discharge experienced lower levels of *tangible support* than those without readmissions.

No correlations were detected between SOC and MOS or its subscales.

5.3 Paper III

Long-term recovery after colorectal cancer surgery among the old: a qualitative study

The third paper explore the experience of persons ≥80 years of age during recovery up to two years after curative CRC surgery.

One main theme identified during the analysis was *Recovery among older persons is a complex process.* It became clear that several factors affected recovery among older persons and could be divided into two sub-themes, *Individual factors affect CRC recovery* and *External support systems facilitate and impede CRC recovery*.

The first sub-theme, *Individual factors affect CRC recovery,* concerns the internal facilitators of and barriers to recovery. Barriers to recovery included recovery as a process with its associated challenges and other health problems that shifted focus away from recovery. Identified facilitators included the inner strength of the older person and their ability to strive for independence while receiving aid if necessary.

The second sub-theme, *External support systems facilitate and impede CRC recovery,* describes how support from family, friends and healthcare personnel bridges the gap caused by unmet needs in recovery. The findings show that the family helps with practical as well as emotional support, making the patient feel seen and appreciated. Help from healthcare providers is usually given right after discharge from the hospital and gradually reduced as the need diminishes and the older person becomes more self-reliant. At the same time, the external support system can create problems in recovery when the expectations of the healthcare service become too big a responsibility for the older person and when there is an imbalance between expected support and reality.

5.4 Merging of the thesis findings

The merging of the studies resulted in the emergence of four themes. Table 5 gives an overview of the synthesis with the themes. The qualitative and quantitative data from the studies have few discrepancies but rather indicate a complementary symbiosis where each study reveals a unique perspective on postoperative recovery among older patients undergoing surgery.

Table 5 – Joint display of findings from Studies 1–3, with common themes

Themes	Study 1	Study 2	Study 3
Recovery as a challenging process	- Early recovery complications, problems and reduced function - Concerned with rehabilitation and overcoming challenges - Stoma is an extra burden	- 32.6% re-admitted shortly after discharge - Of all the participants, 64.8% had an ECOG of 1, 11.1% had an ECOG of 2 and 7.4% had an ECOG of 3.	- Long-term recovery - Started to normalise and adapt to their new everyday life - Distinction between initial and persistent symptoms - Other health issues took focus away from recovery - Physical function still below preoperative levels
The perseverant older person	- Creative solutions - Prepared for discomfort - Previous experience with cancer - Striving for independence	- SOC similar in men and women - SOC correlates to physical function - SOC scores lower in recipients of homecare nursing	- Do not want to be a burden - Previous experience with cancer - Acquiring new knowledge - Being realistic about own limitations - Acquiring aids for daily living
External support as a resource	- Social support as an important resource for safety shortly after discharge - Healthcare services as well as family and friends	- Correlation between re-admittance and lower perceived social support levels - Women report higher levels of perceived social support than men	- Social support as an important resource - Family provides psychosocial and practical support - Healthcare service to call if needed - Healthcare personnel help with procedures and assistance in acute situations
Opportunities for advancement in healthcare services	- Disconnectedness from healthcare services - Lack of information - Responsibility for follow-up care	(No findings)	- Responsibility for follow up and other healthcare tasks - Discrepancy between expected and provided support - E-health communication - Municipality lack substitution services when family is lacking

Recovery as a challenging process

The findings of Studies 1 and 3 show that recovery in both the short- and the long-term can be challenging for the older person. In Study 1, a picture of complications, reduced function and challenges is painted. Informants that underwent additional treatment such as adjuvant treatment experienced more complications and challenges in recovery. Receiving a stoma were described as an additional burden as it required them to find a new normal with the stoma and its associated challenges. In Study 3 a distinction was made between initial and persistent symptoms and the challenges they caused in recovery. These challenges could sometimes lead the older person to lack the capacity to manage recovery. Study 2 found that 32.6% of the older participants were re-admitted shortly after discharging due to reduced general condition, infection or acute abdominal pain.

The older person's focus was centred on rehabilitation and the recovery process (Study 1). In Study 3, the participants had started to normalise everyday life although still affected by the surgery. Other unrelated problems had eclipsed recovery. The older participants often suffered from other health problems and chronic diseases, which could result in additional challenges in recovery (Study 3). Study 3 found that several participants experienced reduced physical function compared to before the surgery. In Study 2, 64.8% had an ECOG of 1 (experiencing restrictions in strenuous physical activity but ambulatory and able to carry out light work), while 11.1% had an ECOG of 2 (ambulatory and capable of all self-care but unable to carry out any work activities) and 7.4 % had an ECOG of 3 (only limited capacity for self-care and confined to the bed or chair for more than 50% of waking hours). The recovery process itself had varying lengths of time during which persistent symptoms became an integrated part of everyday life.

The perseverant older person

In both Studies 1 and 3, previous knowledge and familiarity with cancer were described to make participants more robust towards the psychological strain of the cancer diagnosis, treatment and recovery. The participants described discomfort to be unavoidable under the circumstances and found creative solutions when facing problems (Study 1). Coinciding in Studies 1 and 3 were the striving for independence and the fear of becoming a burden. This was mitigated in Study 3, in certain cases, with the procurement of aids for daily living, such as mobility equipment. Study 2 found the SOC to be similar between men and women. SOC was found to have a strong correlation with physical function; furthermore, SOC was significantly lower in patients who received home care nursing as compared to those who managed on their own. Study 3 described how patients, especially those with a stoma, acquired new knowledge and abilities to achieve independence in this new situation. Some participants also conceded to having surpassed their own limitations to an unhealthy degree in an endeavour to remain independent. Others acquired self-help aids, enabling them to stay self-reliant.

External support as a resource

Social support was described as a valuable and needed resource for recovery among older persons. The findings of both the qualitative studies (1 and 3) refer to social support as an important resource in recovery for practical tasks but also for psychological support. Social support was described as safety shortly after discharge, although needed in varying extent. It could be healthcare services or social network providing this support (Study 1). Family was described to provide psychosocial and practical support (Study 3). Homecare nursing was an important resource in aiding with self-care at home in short-term recovery (Study 1). Further into long-term recovery, homecare nursing assisted with performing necessary procedures, aided in acute situations and was reachable by telephone if assistance was needed (Study 3). Study 2 found a correlation between readmission and lower perceived social support levels between 1 and 5 years postoperatively. Additionally, women reported higher levels of perceived social support than men, indicating that women tended to perceive social support as more available than men.

Opportunities for advancement in healthcare services

Study 1 describes a disconnectedness from healthcare services in short-term recovery. Participants describe suddenly being made responsible for their follow-up care, sometimes lacking the information and knowledge to do this properly, and being left responsible for follow-up requirements (Study 1). This is corroborated in Study 3 and described as a problem continuing into long-term recovery. In Study 3, the responsibility for follow-up care and e-health services was more prominent and described as affecting the participants more negatively. Another point brought up regarding long-term recovery (Study 3) was the notion of a discrepancy between expected and provided support, wherein participants did not receive the services they expected. When they lacked family to help with practical tasks, shortcomings were described in addressing some of the recovery tasks. No evidence was found in Study 2 that substantiated this sub-theme.

6 Discussion

In this chapter, the principal findings from the side-by-side comparison of the studies (1–3) are interpreted in the context of the theoretical background of the thesis and previous research. Finally, methodological considerations are presented.

6.1 Principal findings

The overall aim of this thesis was to investigate the psychosocial and physical factors that are important for recovery after curative CRC surgery among persons ≥80 years old. Qualitative interviews were conducted shortly after discharge and into long-term recovery in addition to the performance of a cross-sectional study 1 to 5 years after CRC treatment among older persons.

The findings demonstrate that recovery is a complex process and time of vulnerability for the older person; however, these patients exude a perseverant rationality in their actions to overcome adversity. Support from social networks and healthcare services is an important resource for recovery, and the current healthcare setup for older patients after CRC surgery has flaws.

6.1.1 Recovery as a challenging process

The findings in Study 1 and 3 indicate that postoperative recovery can be a challenging time for the older person, with unique challenges.

First, in Study 1 a picture of complications, reduced physical function and psychosocial challenges is painted. These findings are corroborated in Study 3, where a further distinction is made between initial and persistent symptoms and their associated challenges in recovery. This is in line with another Norwegian study, which found that 19% of older frail patients experienced complications after discharge (Ommundsen et al., 2018). In addition to the toll this experience takes on the older person comes the responsibility of organizing the necessary medical treatment and homecare nursing, which is seen to be an extra burden in recovery (Sav et al., 2021) and could impact psychosocial and physical functional outcomes (Norlyk & Harder, 2011; Sav et al., 2017). SOC was found to have a strong correlation to physical function (Study 2), and the participants reported reduced physical function up to 2 years after treatment compared to their preoperative condition (Study 3). These findings are corroborated by research finding decreased physical function up to 28 months after surgery in older patients with CRC (Rønning et al., 2014). This limitation affected the participants' ability to perform everyday tasks and health-promoting activities, participate in social life and regain autonomy. Research on younger patients in CRC recovery found that restoring the physical body and regaining a sense of autonomy dominated the first months after surgery (Beech et al., 2012). Younger participants had, for the most part, recovered by 6 months postoperatively and returned to normal life, although sometimes with persistent symptoms of disease (Jakobsson et al., 2017). This could indicate that older persons experience a prolonged recovery compared to their younger counterparts, suggesting that follow-up care by healthcare services such as GPs and homecare nursing is an important aspect of the cancer trajectory in older cancer patients (Moser et al., 2021).

Furthermore, although readmittance to the hospital after CRC surgery is common, a readmittance rate of 32.6% was found in Study 2, a much higher value than the previously reported value among all ages of approximately 14% (Bennedsen et al., 2018; Lucas et al., 2014). However, this result is corroborated by previous research on older patients aged ≥80 years, which showed a readmittance rate twice that of younger patients (Kunitake et al., 2010). Other studies have shown difficulties in explaining the factors underlying readmittance using administrative data (Brauer et al., 2019; Morris et al., 2016). Although

Study 2 has a small sample size, a correlation between readmittance and social support was found that should be further investigated. With a higher readmittance rate among older patients after CRC surgery, there is a need for robust strategies to improve quality of care through early detection of need for help and guide interventions to decrease future unplanned readmittance among older persons after CRC surgery.

Older persons in general are also more likely to suffer from chronic conditions or other health problems compared to younger persons, which is also the case for older patients diagnosed with CRC. Research shows that after cancer treatment, older persons have on average five comorbidities, with two emerging after the cancer treatment (Leach et al., 2015). The coexistence of cancer and other health problems such as other chronic conditions can create complex interrelationships. The first year after treatment, CRC patients show a higher use of primary healthcare services than the general population (Brandenbarg et al., 2014). Chronic conditions and new illnesses can result in additional challenges and eclipsed recovery, shown in Study 3. With a growing number of older persons recovering from CRC, healthcare personnel need to understand the unique impact it has on recovery and establish strategies to optimize care. Antonovsky proposed seeing health and illness as different points on a continuum rather than as a dichotomy (Erikssson & Lindström, 2015). Thus, the focus should be on understanding what moves an individual towards health on the continuum (Antonovsky, 1979). The older person's capacity to cope with chronic conditions needs to be assessed to understand how healthcare services can enhance their care arrangements (Sidell, 2009).

Research also shows that stressful life events such as receiving a cancer diagnosis and undergoing the required treatment can alter a person's SOC, even late in life (Antonovsky, 2012; Nilsson et al., 2003; Volanen et al., 2007). This is especially true for those with a moderate to low SOC. These challenges throughout recovery could affect the older person's capacity to cope.

6.1.2 The perseverant older person

Both qualitative studies (1 and 3) found a striking inner strength in the older persons recovering from CRC surgery. Previous experience with cancer was described to protect against the psychological strain of the cancer diagnosis, treatment and recovery. Older persons were found to seemingly adjust better psychologically after a cancer diagnosis (Cohen et al., 2014). The life experiences the older individuals have accumulated over the years can strengthen their SOC and shape their perception of the cancer trajectory and challenges experienced and enable the appropriate use of coping strategies. Individuals with a high SOC are thought to respond to stressful situations with adaptive health behaviour (Horsburgh & Ferguson, 2012). An individual with a high SOC will be inclined to experience stress, despite the tension, as understandable and predictable (comprehensible). A high SOC will, of course, not guarantee a good outcome; however, it will give an impression of what is needed to overcome the stressful situation and provide the motivation to take action (manageable and meaningful). Furthermore, a higher SOC has been shown to predict a lower incidence of stressful events in older persons with cancer (Sarenmalm et al., 2013b).

Coinciding in Studies 1 and 3 was the striving for independence. One of the most important outcomes of CRC surgery among older persons relates to their physical function and ability to stay independent. Their autonomy and independence can be threatened when they have to rely on others for help. A study found that 18% of patients ≥80 years of age undergoing CRC surgery experience a loss of independence afterwards (Gearhart et al., 2020). Maintaining independence is considered an important patient outcome after CRC surgery (Mohamed et al., 2022). To maintain independence, older persons adjust their coping strategies to deal with the challenges they encounter. In Study 1, creative solutions were described to handle challenges, while in Study 3, new knowledge was acquired and aids, such as moving aids, were procured.

6.1.3 External support as a resource

The findings of both the qualitative studies (1 and 3) indicate social support as an important resource in recovery from CRC surgery. This is corroborated by previous research, which found relationships to be of great importance for persons after cancer treatment (Çakir et al., 2021; Haviland et al., 2017; Kadambi et al., 2020). Relationships with family members and children in particular had great importance in terms of emotional support, giving meaning to life and the motivation to keep going (Harrop et al., 2017; Kvåle & Synnes, 2013; Strang & Strang, 2001), in line with SOC. A person with a high degree of meaningfulness will find meaning in their environment and muster energy to tackle stressful situations (Antonovsky, 1987).

An important consideration in old age is the change in the size and function of supportive networks in later life. Older persons report declining contact with friends, a decreasing network and lower satisfaction with support (Peerenboom et al., 2015). Both Studies 1 and 3 found older persons recovering from CRC surgery to rely on external support. In cases where the supportive network was limited, healthcare services were more present (Study 3). A study from the Netherlands found older persons recovering from CRC to have a higher level of utilization of primary care services and contact with their GP than younger persons after CRC surgery and the general population the first year after surgery (Brandenbarg et al., 2014). The healthcare utilization of older individuals integrated into functional social relationships differs from that of older persons who are socially isolated (Bremer et al., 2017). The findings also showed that older persons were in need of practical assistance from family and friends. Study 2 found a correlation between readmittance and lower perceived social support levels between 1 and 5 years postoperatively. Further research is needed on the role of social support around discharge and interventions to facilitate a better transition to the home to prevent readmissions.

6.1.4 Opportunities for advancement in healthcare services

The findings of Studies 1 and 3 indicate that there are several structural challenges in the follow-up care of older persons in recovery from CRC surgery. This is a recurrent theme in both qualitative studies (1 and 3) and illustrates a disconnectedness between the participants and healthcare services that begins shortly after discharge and continues long into recovery.

In both qualitative studies (1 and 3), the participants described being left responsible for follow-up requirements, which could be described as a burden in recovery. An important aspect of the systematic follow-up program is the detection of disease recurrence, and a criterion for inclusion in the program is the capability to endure surgical and oncologic treatment for the recurrence (The Norwegian Directorate of Health, 2021; Norum et al., 1997). Furthermore, the psychological outcomes of participation in a systematic follow-up program are not only positive in the sense of being disease-free. Participation in the program and testing can also lead to distress caused by false-positive tests (Jeffery et al., 2019) or the scope and logistics of the test, such as in Studies 1 and 3. One can question if follow-up care directed towards identifying and treating the complications and long-term effects of the cancer and its treatment would be more appropriate for the older person after CRC treatment.

Already in 2005, the Institute of Medicine in the USA highlighted the healthcare needs of persons living beyond cancer treatment. In addition to surveillance for recurrence and treatment for the long-term and late effects of the cancer and the treatment, the institute highlighted the care of comorbid conditions (Hewitt et al., 2005). Quality comorbidity care is especially relevant for older persons as they are statistically more likely to have health problems in addition to their cancer. Following the specialization of medicine, within specialist healthcare services, healthcare personnel may not be skilled in managing older cancer patients optimally due to their wide spectrum of comorbid conditions, the intrinsic relationship between the comorbid conditions and polypharmacy (Levit et al., 2013). With improvements in diagnostics and treatments for CRC, more persons are living beyond cancer and into recovery, increasing the importance of care coordination. There is a need for the coordination of the older patient's healthcare needs, including healthcare services provided by a multidisciplinary team consisting of nurses, doctors and allied health professionals with appropriate specializations (Walsh et al., 2010).

Information and proper knowledge to manage self-care were reported to be lacking (Study 1). Study 3 showed a discrepancy between expected and provided support, where patients described not receiving the healthcare services they expected, illustrating an information gap. Information related to cancer and self-care in recovery can be overwhelming. Older persons with cancer report that information regarding self-care at home could be improved, although the appraisal of needed information varies (Hamaker et al., 2022). Having the ability to anticipate symptoms and access desired information can provide an increased feeling of control in recovery and improve coping ability (Lehmann et al., 2020; Li et al., 2011). Additionally, persons with CRC report fewer opportunities to seek advice and discuss their illness with family or friends compared to persons with other cancers (Nagler et al., 2010). In fact, research shows that the recall of medical information by cancer patients is poor (Lehmann et al., 2020). Therefore, education of older cancer patients should be tailored to the individual's needs and abilities to improve their coping ability (Posma et al., 2009).

This thesis identified that some of the challenges encountered by older persons in recovery from CRC surgery are not necessarily a consequence of the health of the patient, but rather the lack of organisation and coordination of the follow-up care and healthcare services provided.

6.2 Methodological considerations

In this thesis, a multiphase mixed methods research design was chosen to explore the psychosocial and physical factors that are important for recovery after curative CRC surgery among persons ≥80 years old, applying both qualitative and quantitative methods. In this section, methodological considerations are presented.

The thesis design utilizes a combination of both qualitative and quantitative research methods. A combination of qualitative and quantitative data can provide a greater breadth and depth of understanding of the phenomenon studied (Creswell & Clark, 2017; Polit & Beck, 2021) in addition to different perspectives of the phenomenon (Creswell & Clark, 2017). The studies in this thesis were performed separately, with no mixing of qualitative and quantitative methods in the respective studies. Data were integrated between Phase 1 and Phase 2, as findings from Study 1 informed the development of the theory and questionnaire utilized in Study 2. Further integrations were conducted between the findings of Studies 1 and 2 that thereafter informed Study 3. The findings from the individual studies were merged in the results of the thesis. The complementary relationship between the studies achieves the overall aim of the thesis (Tashakkori & Teddlie, 2010).

The thesis theoretical framework can be seen as both a limitation and a strength. The inductive approach to the research subject limited the utility of theory in the first study since no theory was chosen before this study was completed. Since recovery from CRC is a little-researched area, it was appropriate to apply a broad approach to be able to describe recovery among older persons as they experience it. However, the findings from Study 1 laid the foundation for the theory used in Studies 2 and 3. The use of the much-researched salutogenesis theory and the concept of SOC to understand health-promoting aspects and factors in recovery is a strength.

The sample in Studies 2 and 3 may be positively skewed because of the sampling method, wherein the participants themselves had to take action to participate in the study. Thus, the most resourceful patients could be overrepresented in this sample; however, convenience sampling was necessary to recruit eligible participants. Nevertheless, the studies showed variety in the characteristics of the participants.

The sample in Study 2 can be considered small (56 participants). Since there is no systematic long-term contact with healthcare services for this group of patients during recovery, recruitment had to be based on invitations sent by mail to access this patient group without applying undue pressure to participate. However, a response rate of 47% can be considered satisfactory when surveying patients with a median age of 86 years, and can be perceived as a method to created new hypotheses.

The COVID-19 outbreak challenged the conduction of conventional face-to-face interviews for data collection. Older persons recovering from CRC surgery were considered a vulnerable group of individuals at risk for this disease. Given the outbreak, visitation restrictions hindered the researcher in meeting participants face-to-face (Juranek & Zoutman, 2020). There are other ways to collect qualitative data without face-to-face proximity. However, none of the methods identified were able to adequately replace the face-to-face interview with persons ≥ 80 years of age; therefore, data collection was paused for several months until it was considered safe to continue.

In Study 2 data were collected from different points in time. The questionnaire was collected from persons in long-term recovery, while clinical data were collected from the patients' journals at the time of surgery. This was the only method that allowed for the exploration of the correlation between clinical data and patient-reported data, which could thereby provide insights into the correlation between the clinical data at the time of surgery and the coping ability during long-term recovery.

7 Conclusion

The findings of this thesis provide valuable knowledge for healthcare personnel in contact with older persons curatively treated for CRC in addition to policymakers and the public. The thesis provides insights into the older person's experiences (Studies 1 and 3) and perceptions (Study 2) of psychosocial and physical factors important in recovery after curative CRC surgery and challenges faced during recovery, all in the context of the health-promoting theory of salutogenesis.

Recovery is described as a complex process including a unique set of challenges for older CRC patients, such as prolonged recovery, initial and persistent symptoms, complications, rehabilitation and other health problems that can eclipse recovery. These challenges can continue into long-term recovery. Despite or because of these challenges, older persons demonstrate perseverance through their described actions. By having a realistic perspective of their own limitations, being prepared for potential challenges moving forward and being creative in the resolution of challenges, they manage the situations they face with a deep drive to remain independent in their endeavours. However, social support is clearly reflected as an important resource by the data. Social support can stem from social networks or healthcare services, and there is great variation in the needed support with respect to time and tasks from short- to long-term recovery. Perceived support was found to correlate with readmission after discharge and was described as a resource for safety in the transition process from hospital to home.

An increasing older population and improvements in diagnostics and treatments will result in an increase in the number of older persons living beyond cancer treatment and into recovery, thus raising the importance of follow-up care for older patients. Therefore, the abovementioned improvements are accompanied by new challenges for appropriate follow-up care. A new way of working with older persons after curative

CRC treatment may be to provide the older persons with the opportunity to maintain control when depending on others for assistance.

The number and nature of the challenges related to older persons' recovery from curative CRC surgery identified in this thesis require multiple approaches from healthcare services to address them, with implications for clinical practice and further research.

7.1 Implications for practice

The findings of this thesis are applicable for the improved facilitation of follow-up care after CRC surgery among the old, regarding both specialist healthcare services and primary healthcare services. The findings provide information on challenges experienced in recovery and should thus provide a direction for the improvement of the follow-up care of older patients after CRC surgery. This information is not only relevant to healthcare personnel in contact with this group of patients (in both specialist healthcare services and primary healthcare services) but also to policymakers and researchers. Below is a list of key strategies to improve practices in follow-up care after CRC surgery among older persons.

The findings are of importance for healthcare personnel in contact with older patients with CRC before treatment. Information regarding recovery and physical functional decline can help older patients to set realistic expectations for surgical outcomes as well as inform the decision to undergo treatment.

There is a need to focus on efforts to improve communication and collaboration between specialist and primary healthcare services to deliver more holistic and coordinated follow-up care.

Establishing routines for incorporating social networks as partners in follow-up care throughout recovery is needed. This work should be planned during treatment to prepare the social network for the coming tasks before discharge, thus making the transition from hospital to home as seamless as possible for the patient.

There should be increasing awareness of the organizational burden that follows complex health conditions when adding follow-up care for cancer among older persons. There is a need for greater focus on the impact of comorbidities on recovery among older patients. Efforts to improve facilitation by healthcare personnel or coordinators can ease this burden.

There should be developed routines for systematically providing information regarding the challenges and complications the older patients may encounter after CRC surgery and discharge, as well as information on how to self-manage these challenges and when it is appropriate to seek medical attention, apart from providing necessary contacts for when support is needed. This is imperative for the patient's understanding of their situation and ability to cope.

7.2 Suggestions for future research

Since there is little research on the experience of recovery after CRC surgery and the possible challenges that older persons encounter, this thesis lays an important and necessary foundation to underpin and guide future research on older persons recovering from CRC surgery.

There is a need for more knowledge of the relationship between social support, psychosocial and physical factors in general and readmittance through larger longitudinal studies of recovery among older persons after CRC surgery.

The findings of this thesis may provide valuable information for interventional studies aimed at optimizing follow-up care for older persons. Follow-up care and psychosocial support should be prioritized above the detection of recurrence. Facilitating improved psychosocial support directly after discharge, including the organization and logistics of healthcare appointments related to other comorbid conditions, is important, in addition to psychosocial support from specialized healthcare personnel when needed.

Further research is also needed from a superior healthcare perspective to develop a consensus on the amount and type of follow-up care required after surgery, which not only encompasses recurrence detection but also focuses on the care and psychosocial and physical support required by the older person after surgery to remain as independent as possible.

Larger studies should also be performed to further explore the relationship between coping capacity and social support in older persons with CRC and the influencing factors identified in this thesis.

8 References

Aaronson, N. K., Mattioli, V., Minton, O., Weis, J., Johansen, C., Dalton, S. O., Verdonck-de Leeuw, I. M., Stein, K. D., Alfano, C. M., & Mehnert, A. (2014). Beyond treatment–Psychosocial and behavioural issues in cancer survivorship research and practice. *European Journal of Cancer Supplements*, *12*(1), 54-64.

Ahmad, M., Khan, M. A., & Shirazi, M. (2013). Perception of social support by cancer patients. *International Journal of Psychology and Behavioral Sciences*, *3*(5), 115-122.

Aldwin, C. M., Igarashi, H., Gilmer, D. F., & Levenson, M. R. (2017). *Health, illness, and optimal aging: Biological and psychosocial perspectives*. Springer Publishing Company.

Allvin, R., Berg, K., Idvall, E., & Nilsson, U. (2007). Postoperative recovery: a concept analysis. *Journal of Advanced Nursing*, *57*(5), 552-558.

Anaya, D. A., Becker, N. S., & Abraham, N. S. (2011). Global graying, colorectal cancer and liver metastasis: new implications for surgical management. *Critical Reviews in Oncology/ Hematology*, *77*(2), 100-108.

Antonovsky, A. (1979). Health, stress, and coping. *New perspectives on mental and physical well-being*, Jossey-bass. 12-37.

Antonovsky, A. (1987). *Unraveling the mystery of health: How people manage stress and stay well*. Jossey-bass.

Antonovsky, A. (2012). *Helsens mysterium: den salutogene modellen*. Gyldendal akademisk.

World Medical Association. (2018). *WMA Declaration of Helsinki - Ethical Principles for Medical Research Involving Human Subjects*. http://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/

Aziz, N. M. (2007). Cancer survivorship research: state of knowledge, challenges and opportunities. *Acta Oncologica*, *46*(4), 417-432.

Bagnall, N., Malietzis, G., Kennedy, R., Athanasiou, T., Faiz, O., & Darzi, A. (2014). A systematic review of enhanced recovery care after colorectal surgery in elderly patients. *Colorectal Disease*, *16*(12), 947-956.

Balducci, L., & Extermann, M. (2000). Management of cancer in the older person: a practical approach. *The Oncologist, 5*(3), 224-237)

Beech, N., Arber, A., & Faithfull, S. (2012). Restoring a sense of wellness following colorectal cancer: a grounded theory. *Journal of Advanced Nursing*, *68*(5), 1134-1144.

Bennedsen, A., Eriksen, J., & Gögenur, I. (2018). Prolonged hospital stay and readmission rate in an enhanced recovery after surgery cohort undergoing colorectal cancer surgery. *Colorectal Disease*, *20*(12), 1097-1108.

Blaikie, N., & Priest, J. (2019). *Designing social research: The logic of anticipation*. John Wiley & Sons.

Boeckxstaens, P., Vaes, B., De Sutter, A., Aujoulat, I., Van Pottelbergh, G., Matheï, C., & Degryse, J.-M. (2016). A high sense of coherence as protection against adverse health outcomes in patients aged 80 years and older. *The Annals of Family Medicine*, *14*(4), 337-343.

Bos, A., Kortbeek, D., Van Erning, F., Zimmerman, D., Lemmens, V., Dekker, J., & Maas, H. (2019). Postoperative mortality in elderly patients with colorectal cancer: The impact of age, time-trends and competing risks of dying. *European Journal of Surgical Oncology*, *45*(9), 1575-1583.

Brandenbarg, D., Roorda, C., Groenhof, F., Havenga, K., Berger, M. Y., De Bock, G. H., & Berendsen, A. J. (2014). Increased primary health care use in the first year after colorectal cancer diagnosis. *Scandinavian Journal of Primary Health Care*, *32*(2), 55-61.

Brauer, D. G., Lyons, S. A., Keller, M. R., Mutch, M. G., Colditz, G. A., & Glasgow, S. C. (2019). Simplified risk prediction indices do not accurately predict 30-day death or readmission after discharge following colorectal surgery. *Surgery*, *165*(5), 882-888.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77-101.

Bremer, D., Inhestern, L., & von dem Knesebeck, O. (2017). Social relationships and physician utilization among older adults—A systematic review. *PloS One*, *12*(9), e0185672.

Breugom, A. J., Bastiaannet, E., Dekker, J. W. T., Wouters, M. W. J. M., van de Velde, C. J. H., & Liefers, G. J. (2018). Decrease in 30-day and one-year mortality over time in patients aged ≥75 years with stage I–III colon cancer: A population-based study. *European Journal of Surgical Oncology*, *44*(12), 1889-1893.

Browne, S., Dowie, A., Mitchell, E. D., Wyke, S., Ziebland, S., Campbell, N., & Macleod, U. (2011). Patients' needs following colorectal cancer diagnosis: where does primary care fit in? *British Journal of General Practice*, *61*(592), e692-e699.

Çakir, H., Küçükakça Çelik, G., & Çirpan, R. (2021). Correlation between social support and psychological resilience levels in patients undergoing colorectal cancer surgery: a descriptive study. *Psychology, Health & Medicine*, *26*(7), 899-910.

Clarke, V., & Braun, V. (2013). Successful qualitative research: A practical guide for beginners. *Successful Qualitative Research*, 1-400.

Cohen, J. (2013). *Statistical power analysis for the behavioral sciences*. Routledge.

Cohen, M., Baziliansky, S., & Beny, A. (2014). The association of resilience and age in individuals with colorectal cancer: an exploratory cross-sectional study. *Journal of Geriatric Oncology, 5*(1), 33-39.

Cohen, S. (2004). Social relationships and health. *American Psychologist*, *59*(8), 676.

Conill, C., Verger, E., & Salamero, M. (1990). Performance status assessment in cancer patients. *Cancer*, *65*(8), 1864-1866.

Couwenberg, A. M., de Beer, F. S. A., Intven, M. P. W., Burbach, J. P. M., Smits, A. B., Consten, E. C. J., Schiphorst, A. H. W., Wijffels, N. A. T., de Roos, M. A. J., Hamaker, M. E., van Grevenstein, W. M. U., & Verkooijen, H. M. (2018). The impact of postoperative complications on health-related quality of life in older patients with rectal cancer; a prospective cohort study. *Journal of Geriatric Oncology*, *9*(2), 102-109.

Creswell, J. W. (1999). Mixed-method research: Introduction and application. In *Handbook of Educational Policy* (pp. 455-472). Elsevier.

Creswell, J. W., & Clark, V. L. P. (2017). *Designing and Conducting Mixed Methods Research.* Sage Publications.

Creswell, J. W., & Poth, C. N. (2016). *Qualitative inquiry and research design: Choosing among five approaches*. Sage publications.

Dekker, J. W., van den Broek, C. B., Bastiaannet, E., van de Geest, L. G., Tollenaar, R. A., & Liefers, G. J. (2011). Importance of the first postoperative year in the prognosis of elderly colorectal cancer patients. *Annals of Surgical Oncology*, *18*(6), 1533-1539.

Devon, K. M., Urbach, D. R., & McLeod, R. S. (2011). Postoperative disposition and health services use in elderly patients undergoing colorectal cancer surgery: a population-based study. *Surgery*, *149*(5), 705-712.

Drageset, J., Eide, G. E., Nygaard, H. A., Bondevik, M., Nortvedt, M. W., & Natvig, G. K. (2009). 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. *International Journal of Nursing Studies*, *46*(1), 66-76.

Drageset, J., Espehaug, B., Hallberg, I. R., & Natvig, G. K. (2014). Sense of coherence among cognitively intact nursing home residents–a five-year longitudinal study. *Aging & Mental Health*, *18*(7), 889-896.

Drageset, J., Espehaug, B., & Kirkevold, M. (2012). The impact of depression and sense of coherence on emotional and social loneliness among nursing home residents without cognitive impairment–a questionnaire survey. *Journal of Clinical Nursing*, *21*(7-8), 965-974.

Drageset, J., Nygaard, H. A., Eide, G. E., Bondevik, M., Nortvedt, M. W., & Natvig, G. K. (2008). Sense of coherence as a resource in relation to health-related quality of life among mentally intact nursing home residents–a questionnaire study. *Health and Quality of Life Outcomes*, *6*(1), 85.

Eagle, D. E., Hybels, C. F., & Proeschold-Bell, R. J. (2019). Perceived social support, received social support, and depression among clergy. *Journal of Social and Personal Relationships*, *36*(7), 2055-2073.

Eom, C.-S., Shin, D. W., Kim, S. Y., Yang, H. K., Jo, H. S., Kweon, S. S., Kang, Y. S., Kim, J.-H., Cho, B.-L., & Park, J.-H. (2013). Impact of perceived social support on the mental health and health-related quality of life in cancer patients: results from a nationwide, multicenter survey in South Korea. *Psycho-Oncology*, *22*(6), 1283-1290.

Eriksson, M. (2017). The sense of coherence in the salutogenic model of health. In *The handbook of salutogenesis* (pp. 91-96). Springer.

Eriksson, M., & Lindström, B. (2005). Validity of Antonovsky's sense of coherence scale: a systematic review. *Journal of Epidemiology & Community Health*, *59*(6), 460-466.

Eriksson, M., & Mittelmark, M. B. (2017). The Sense of Coherence and Its Measurement. *The Handbook of Salutogenesis*, 97-106.

Erikssson, M., & Lindström, B. (2015). *Haikerens guide til salutogenese.* Gyldendal.

European Union. (2021). *Europe's Beating Cancer Plan - Communication from the commission to the European Parliament and the Council*. European Commission.

Fagard, K., Casaer, J., Wolthuis, A., Flamaing, J., Milisen, K., Lobelle, J. P., Wildiers, H., & Kenis, C. (2017). Postoperative complications in individuals aged 70 and over undergoing elective surgery for colorectal cancer. *Colorectal Disease*, *19*(9), O329-O338.

Folkman, S., & Moskowitz, J. T. (2004). Coping: pitfalls and promise. *Annual Review of Psychology*, *55*, 745-774.

Fook, J. (1996). *The reflective researcher: Social workers' theories of practice research*. Allen & Unwin.

Forsmo, H. M., Erichsen, C., Rasdal, A., Körner, H., & Pfeffer, F. (2017). Enhanced recovery after colorectal surgery (ERAS) in elderly patients is feasible and achieves similar results as in younger patients. *Gerontology and Geriatric Medicine*, *3*, 2333721417706299.

Gearhart, S. L., Do, E. M., Owodunni, O., Gabre-Kidan, A. A., & Magnuson, T. (2020). Loss of independence in older patients after operation for colorectal cancer. *Journal of the American College of Surgeons*, *230*(4), 573-582.

Graneheim, U. H., Lindgren, B.-M., & Lundman, B. (2017). Methodological challenges in qualitative content analysis: A discussion paper. *Nurse Education Today*, *56*, 29-34.

Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, *24*(2), 105-112.

Greene, J. C., Caracelli, V. J., & Graham, W. F. (1989). Toward a conceptual framework for mixed-method evaluation designs. *Educational Evaluation and Policy Analysis*, *11*(3), 255-274.

Greene, M. J. (2014). On the inside looking in: Methodological insights and challenges in conducting qualitative insider research. *The Qualitative Report*, *19*(29), 1-13.

Hamaker, M. E., van Walree, I. C., Seghers, P. A. N., van den Bos, F., Soubeyran, P., O'Hanlon, S., & Rostoft, S. (2022). Information needs of older patients newly diagnosed with cancer. *Journal of Geriatric Oncology*, *13*(3), 265-272.

Harrop, E., Noble, S., Edwards, M., Sivell, S., Moore, B., & Nelson, A. (2017). Managing, making sense of and finding meaning in advanced illness: a qualitative exploration of the coping and wellbeing experiences of patients with lung cancer [Article]. *Sociology of Health & Illness*, *39*(8), 1448-1464.

Haugan, G., & Rannestad, T. (2014). Helsefremming i kommunehelsetjenesten. [Health promotion in primary healthcare]. *Cappelen Damm Forlag*.

Haviland, J., Sodergren, S., Calman, L., Corner, J., Din, A., Fenlon, D., Grimmett, C., Richardson, A., Smith, P. W., & Winter, J. (2017). Social support following diagnosis and treatment for colorectal cancer and associations with health-related quality of life: Results from the UK ColoREctal Wellbeing (CREW) cohort study. *Psycho-Oncology*, *26*(12), 2276-2284.

Heale, R., & Twycross, A. (2015). Validity and reliability in quantitative studies. *Evidence-based Nursing*, *18*(3), 66-67.

The Norwegian Departement of Health. (2020). *Cancer in Norway 2019- Cancer incidence, mortality, survival and prevalence in Norway*. The Norwegian Directorate of Health.

The Norwegian Departement of Health. (2021). *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]*.

Hewitt, M., Greenfield, S., & Stovall, E. (2005). *From cancer patient to cancer survivor: lost in transition*. National Academies Press.

Hewitt, M., Rowland, J. H., & Yancik, R. (2003). Cancer survivors in the United States: age, health, and disability. *The Journals of*

Gerontology Series A: Biological Sciences and Medical Sciences, *58*(1), M82-M91.

Hinz, A., Singer, S., & Brähler, E. (2014). European reference values for the quality of life questionnaire EORTC QLQ-C30: results of a German investigation and a summarizing analysis of six European general population normative studies. *Acta Oncologica*, *53*(7), 958-965.

Horsburgh, M. E., & Ferguson, A. L. (2012). Origins of Health and Sense of Coherence. *Handbook of stress, coping, and health: Implications for nursing research, theory, and practice*, (pp. 175). Sage Publications.

Hvalvik, S. D., S. . (2015). The Transition from Hospital to Home: Older people`s Experiences. *Open Journal of Nursing*, *5*, 622- 631.

Idan, O., Eriksson, M., & Al-Yagon, M. (2017). The salutogenic model: the role of generalized resistance resources. In *The handbook of salutogenesis* (pp. 57-69). Springer.

Jakobsson, J., Idvall, E., & Kumlien, C. (2017). The lived experience of recovery during the first 6 months after colorectal cancer surgery. *Journal of Clinical Nursing*, *26*(23-24), 4498-4505.

Jatoi, A., Muss, H., Allred, J. B., Cohen, H. J., Ballman, K., Hopkins, J. O., Gajra, A., Lafky, J., Wolff, A., & Kottschade, L. (2016). Social support and its implications in older, early-stage breast cancer patients in CALGB 49907 (Alliance A171301). *Psycho-Oncology*, *25*(4), 441-446.

Jeffery, M., Hickey, B. E., & Hider, P. N. (2019). Follow-up strategies for patients treated for non-metastatic colorectal cancer. *Cochrane Database of Systematic Reviews*(9). John Wiley & Sons.

Johnson, R. B., & Onwuegbuzie, A. J. (2004). Mixed methods research: A research paradigm whose time has come. *Educational Researcher*, *33*(7), 14-26.

Jorgensen, M. L., Young, J. M., Harrison, J. D., & Solomon, M. J. (2012). Unmet supportive care needs in colorectal cancer: differences by age. *Supportive Care in Cancer*, *20*(6), 1275-1281.

Juranek, S., & Zoutman, F. (2020). The effect of social distancing measures on the demand for intensive care: Evidence on covid-19 in scandinavia. (No. 8262). CESifo Working Paper.

Kadambi, S., Soto-Perez-de-Celis, E., Garg, T., Loh, K. P., Krok-Schoen, J. L., Battisti, N. M. L., Moffat, G. T., Gil-Jr, L. A., Mohile, S., & Hsu, T. (2020). Social support for older adults with cancer: Young International Society of Geriatric Oncology review paper. *Journal of Geriatric Oncology*, *11*(2), 217-224.

Kenne Sarenmalm, E., Browall, M., & Gaston-Johansson, F. (2014). Symptom burden clusters: a challenge for targeted symptom management. A longitudinal study examining symptom burden clusters in breast cancer. *Journal of Pain & Symptom Management*, *47*(4), 731-741.

Kimberlin, C. L., & Winterstein, A. G. (2008). Validity and reliability of measurement instruments used in research. *American Journal of Health-system Pharmacy*, *65*(23), 2276-2284.

Kirkevold, M., Brodtkorb, K., & Ranhoff, A. H. (2014). *Geriatrisk sykepleie: god omsorg til den gamle pasienten* (2. utg. ed.). Gyldendal akademisk.

Kunitake, H., Zingmond, D. S., Ryoo, J., & Ko, C. Y. (2010). Caring for Octogenarian and Nonagenarian Patients with Colorectal Cancer: What Should Our Standards and Expectations Be? *Diseases of the Colon & Rectum*, *53*(5), 735-743.

Kvåle, K., & Synnes, O. (2013). Understanding cancer patients` reflections on good nursing care in light of Antonovsky's theory. *European Journal of Oncology Nursing*, *17*(6), 814-819.

Langford, C. P. H., Bowsher, J., Maloney, J. P., & Lillis, P. P. (1997). Social support: a conceptual analysis. *Journal of Advanced Nursing*, *25*(1), 95-100.

Le Berre, M., Maimon, G., Sourial, N., Gueriton, M., & Vedel, I. (2017). Impact of transitional care services for chronically ill older patients: a systematic evidence review. *Journal of the American Geriatrics Society*, *65*(7), 1597-1608.

Leach, C. R., Weaver, K. E., Aziz, N. M., Alfano, C. M., Bellizzi, K. M., Kent, E. E., Forsythe, L. P., & Rowland, J. H. (2015). The complex health profile of long-term cancer survivors: prevalence and predictors of comorbid conditions. *Journal of Cancer Survivorship*, *9*, 239-251.

Lehmann, V., Labrie, N. H. M., van Weert, J. C. M., van Dulmen, S., de Haes, H. J. C. J. M., Kersten, M. J., Pieterse, A. H., & Smets, E. M. A. (2020). Provider caring and structuring treatment information to improve cancer patients' recall: Does it help? *Patient Education and Counseling*, *103*(1), 55-62.

Levit, L. A., Balogh, E., Nass, S. J., & Ganz, P. (2013). *Delivering high-quality cancer care: charting a new course for a system in crisis*. The National Academies Press.

Li, L. T., Barden, G. M., Balentine, C. J., Orcutt, S. T., Naik, A. D., Artinyan, A., Sansgiry, S., Albo, D., Berger, D. H., & Anaya, D. A. (2015). Postoperative transitional care needs in the elderly: an outcome of recovery associated with worse long-term survival. *Annals of Surgery*, *261*(4), 695-701.

Li, P. W., So, W. K., Fong, D. Y., Lui, L. Y., Lo, J. C., & Lau, S. (2011). The information needs of breast cancer patients in Hong Kong and their levels of satisfaction with the provision of information. *Cancer Nursing*, *34*(1), 49-57.

Lincoln, Y. S., & Guba, E. G. (1985). Establishing trustworthiness. *Naturalistic Inquiry*, *289*(331), 289-327.

Lindgren, B.-M., Lundman, B., & Graneheim, U. H. (2020). Abstraction and interpretation during the qualitative content analysis process. *International Journal of Nursing Studies*, *108*, 103632.

Lindström, B. (2018). Workshop salutogenesis and the future of health promotion and public health. *Scandinavian Journal of Public Health*, *46*(20_suppl), 94-98.

Ljungqvist, O., Scott, M., & Fearon, K. C. (2017). Enhanced Recovery After Surgery: A Review. *JAMA Surgery*, *152*(3), 292-298.

Lucas, D. J., Ejaz, A., Bischof, D. A., Schneider, E. B., & Pawlik, T. M. (2014). Variation in readmission by hospital after colorectal cancer surgery. *JAMA Surgery*, *149*(12), 1272-1277.

Lund, T. (2005). The qualitative–quantitative distinction: Some comments. *Scandinavian Journal of Educational Research*, *49*(2), 115-132.

Manceau, G., Karoui, M., Werner, A., Mortensen, N. J., & Hannoun, L. (2012). Comparative outcomes of rectal cancer surgery between elderly and non-elderly patients: a systematic review. *The Lancet Oncology*, *13*(12), e525-e536.

Meiklejohn, J. A., Mimery, A., Martin, J. H., Bailie, R., Garvey, G., Walpole, E. T., Adams, J., Williamson, D., & Valery, P. C. (2016). The role of the GP in follow-up cancer care: a systematic literature review. *Journal of Cancer Survivorship*, *10*(6), 990-1011.

Mohajan, H. (2017). Two criteria for good measurements in research: Validity and reliability. *Annals of Spiru Haret University Economics Series, 17*(4), 59-82.

Mohamed, A., Nicolais, L., & Fitzgerald, T. L. (2022). Predicting loss of independence after high-risk gastrointestinal abdominal surgery: Frailty vs. NSQIP risk calculator. *European Journal of Surgical Oncology*, *48*(6), 1433-1438.

Morris, M. S., Graham, L. A., Richman, J. S., Hollis, R. H., Jones, C. E., Wahl, T., Itani, K. M., Mull, H. J., Rosen, A. K., & Copeland, L. (2016). Postoperative 30-day readmission. *Annals of Surgery*, *264*(4), 621-631.

Moser, A., Melchior, I., Veenstra, M., Stoffers, E., Derks, E., & Jie, K. S. (2021). Improving the experience of older people with colorectal and breast cancer in patient-centred cancer care pathways using experience-based co-design. *Health Expectations*, *24*(2), 478-490.

Nagler, R. H., Gray, S. W., Romantan, A., Kelly, B. J., DeMichele, A., Armstrong, K., Schwartz, J. S., & Hornik, R. C. (2010). Differences in information seeking among breast, prostate, and colorectal cancer patients: results from a population-based survey. *Patient Education and Counseling*, *81*, S54-S62.

Nilsen, E. R., Hollister, B., Söderhamn, U., & Dale, B. (2022). What matters to older adults? Exploring person-centred care during and after transitions between hospital and home. *Journal of Clinical Nursing*, *31*(5-6), 569-581.

Nilsson, B., Holmgren, L., Stegmayr, B., & Westman, G. (2003). Sense of coherence-stability over time and relation to health, disease, and psychosocial changes in a general population: a longitudinal study. *Scandinavian Journal of Public Health*, *31*(4), 297-304.

Nordtug, B., Krokstad, S., Sletvold, O., & Holen, A. (2013). Differences in social support of caregivers living with partners suffering from COPD or dementia. *International journal of older people nursing*, *8*(2), 93-103.

Norlyk, A., & Harder, I. (2011). Recovering at home: participating in a fast-track colon cancer surgery programme. *Nursing Inquiry*, *18*(2), 165-173.

Norum, J., Gerner, T., Bergan, A., & Lange, O. (1997). Kontrollopplegg etter potensiell kurativ operasjon for kolorektalcancer-Anbefaling fra Norsk Gastrointestinal Cancer Gruppe. [Control schedule after potential curative surgery for colorectal cancer-Recommendation from the Norwegian Gastrointestinal Cancer Group]. *Tidsskrift for den Norske Laegeforening*, *117*(20), 2965-2968.

Cancer Registry of Norway. (2022). *Årsrapport Nasjonalt kvalitetsregister for tykk- og endetarmskreft 2021. [Annual report for colorectal cancer 2021]*. Cancer Registry of Norway

Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods*, *16*(1), 1609406917733847.

O'Gorman, C., Stack, J., O'Ceilleachair, A., Denieffe, S., Gooney, M., McKnight, M., & Sharp, L. (2018). Colorectal cancer survivors: an investigation of symptom burden and influencing factors. *BMC Cancer*, *18*(1), 1-10.

Ommundsen, N., Nesbakken, A., Wyller, T. B., Skovlund, E., Bakka, A. O., Jordhøy, M. S., & Rostoft, S. (2018). Post-discharge complications in frail older patients after surgery for colorectal cancer. *European Journal of Surgical Oncology*, *44*(10), 1542-1547.

Page, A. E., & Adler, N. E. (2008). *Cancer care for the whole patient: Meeting psychosocial health needs.* The National Academies Press.

Patton, M. Q. (2002). Two decades of developments in qualitative inquiry: A personal, experiential perspective. *Qualitative Social Work*, *1*(3), 261-283.

Peerenboom, L., Collard, R., Naarding, P., & Comijs, H. (2015). The association between depression and emotional and social loneliness in older persons and the influence of social support, cognitive functioning and personality: A cross-sectional study. *Journal of Affective Disorders*, *182*, 26-31.

Pezaro, C., & Jefford, M. (2009). Early stage bowel cancer: Follow up and survivorship. *Australian Family Physician*, *38*(4), 205.

Pitt, B. (1998). Loss in late life. *BMJ*, *316*(7142), 1452-1454.

Plano Clark, V. L., Garrett, A. L., & Leslie-Pelecky, D. L. (2010). Applying three strategies for integrating quantitative and qualitative databases in a mixed methods study of a nontraditional graduate education program. *Field Methods*, *22*(2), 154-174.

Polit, D. F., & Beck, C. T. (2008). *Nursing research: Generating and assessing evidence for nursing practice*. Lippincott Williams & Wilkins.

Polit, D. F., & Beck, C. T. (2021). *Nursing research: Generating and assessing evidence for nursing practice, eleventh edition*. Lippincott Williams & Wilkins.

Ponterotto, J. G., Mathew, J. T., & Raughley, B. (2013). The value of mixed methods designs to social justice research in counseling and psychology. *Journal for Social Action in Counseling & Psychology*, *5*(2), 42-68.

Posma, E. R., van Weert, J., Jansen, J., & Bensing, J. M. (2009). Older cancer patients' information and support needs surrounding treatment: An evaluation through the eyes of patients, relatives and professionals. *BMC Nursing*, *8*(1), 1-15.

Rajabiyazdi, F., Alam, R., Pal, A., Montanez, J., Law, S., Pecorelli, N., Watanabe, Y., Chiavegato, L. D., Falconi, M., Hirano, S., Mayo, N. E., Lee, L., Feldman, L. S., & Fiore, J. F., Jr. (2021). Understanding the Meaning of Recovery to Patients Undergoing Abdominal Surgery. *JAMA Surgery*, *156*(8), 758-765.

Robb, C., Lee, A., Jacobsen, P., Dobbin, K. K., & Extermann, M. (2013). Health and personal resources in older patients with cancer undergoing chemotherapy. *Journal of Geriatric Oncology*, *4*(2), 166-173.

Romøren, T. I., Torjesen, D. O., & Landmark, B. (2011). Promoting coordination in Norwegian health care. *International Journal of Integrated Care*, *11*(Spec 10th Anniversary Ed), e127-e127.

Rønning, B., Wyller, T. B., Jordhøy, M. S., Nesbakken, A., Bakka, A., Seljeflot, I., & Kristjansson, S. R. (2014). Frailty indicators and functional status in older patients after colorectal cancer surgery. *Journal of Geriatric Oncology*, *5*(1), 26-32.

Rønning, B., Wyller, T. B., Nesbakken, A., Skovlund, E., Jordhøy, M. S., Bakka, A., & Rostoft, S. (2016). Quality of life in older and frail patients after surgery for colorectal cancer—a follow-up study. *Journal of Geriatric Oncology*, *7*(3), 195-200.

Samuelsson, K. S., Egenvall, M., Klarin, I., Lökk, J., & Gunnarsson, U. (2019). Preoperative geriatric assessment and follow-up of patients older than 75 years undergoing elective surgery for suspected colorectal cancer. *Journal of Geriatric Oncology*, *10*(5), 709-715.

Samuelsson, K. S., Egenvall, M., Klarin, I., Lökk, J., Gunnarsson, U., & Iwarzon, M. (2018). The older patient's experience of the healthcare chain and information when undergoing colorectal cancer surgery according to the enhanced recovery after surgery concept. *Journal of Clinical Nursing*, *27*(7-8), e1580-e1588.

Sarenmalm, E. K., Browall, M., Persson, L. O., Fall-Dickson, J., & Gaston-Johansson, F. (2013). Relationship of sense of coherence to stressful events, coping strategies, health status, and quality of life in women with breast cancer. *Psycho-Oncology*, *22*(1), 20-27.

Sav, A., McMillan, S. S., & Akosile, A. (2021). Burden of Treatment among Elderly Patients with Cancer: A Scoping Review. *Healthcare*, *9*, 612.

Sav, A., Salehi, A., Mair, F. S., & McMillan, S. S. (2017). Measuring the burden of treatment for chronic disease: implications of a scoping review of the literature. *BMC Medical Research Methodology*, *17*(1), 1-14.

Schag, C., Ganz, P., Wing, D., Sim, M.-S., & Lee, J. (1994). Quality of life in adult survivors of lung, colon and prostate cancer. *Quality of Life Research*, *3*(2), 127-141.

Schreier, M. (2012). *Qualitative content analysis in practice*. Sage publications.

Shapiro, C. L. (2018). Cancer Survivorship. *New England Journal of Medicine*, *379*(25), 2438-2450.

Sherbourne, C. D., & Stewart, A. L. (1991). The MOS social support survey. *Social science & medicine*, *32*(6), 705-714.

Sidell, M. (2009). Older people’s health: Applying Antonovsky’s salutogenic paradigm. *A reader in promoting public health. Challenge and controversy*, 27-32. Sage publications.

Sjolander, C., & Ahlstrom, G. (2012). The meaning and validation of social support networks for close family of persons with advanced cancer. *BMC Nursing*, *11*(1), 1-14.

Sodergren, S. C., Wheelwright, S. J., Permyakova, N. V., et al. (2019). Supportive care needs of patients following treatment for colorectal cancer: risk factors for unmet needs and the association between unmet needs and health-related quality of life—results from the ColoREctal Wellbeing (CREW) study. *Journal of Cancer Survivorship*, *13*(6), 899-909.

Stensletten, K., Bruvik, F., Espehaug, B., & Drageset, J. (2016). Burden of care, social support, and sense of coherence in elderly caregivers living with individuals with symptoms of dementia. *Dementia*, *15*(6), 1422-1435.

Strang, S., & Strang, P. (2001). Spiritual thoughts, coping and 'sense of coherence' in brain tumour patients and their spouses. *Palliative Medicine*, *15*(2), 127-134.

Strasberg, S. M., Linehan, D. C., & Hawkins, W. G. (2009). The accordion severity grading system of surgical complications. *Annals of Surgery*, *250*(2), 177-186.

Sung, H., Ferlay, J., Siegel, R. L., Laversanne, M., Soerjomataram, I., Jemal, A., & Bray, F. (2021). Global cancer statistics 2020: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA: A Cancer Journal for Clinicians*, *71*(3), 209-249.

Tashakkori, A., & Creswell, J. W. (2007). *Exploring the nature of research questions in mixed methods research.* Sage Publications.

Tashakkori, A., & Teddlie, C. (2010). *SAGE Handbook of Mixed Methods in Social & Behavioral Research* (2 ed.) Sage Publications.

Taylor, C. (2000). *Practising reflexivity in health and welfare: Making knowledge.* Open University.

Taylor, S. E. (2011). Social support: A review. In *The Oxford Handbook of Healh Psychology*. Oxford University Press.

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, *19*(6), 349-357.

van Abbema, D., van Vuuren, A., van den Berkmortel, F., van den Akker, M., Deckx, L., Buntinx, F., van Kampen, R., Lambooij, E., de Boer, M., de Vos-Geelen, J., & Tjan-Heijnen, V. C. (2017). Functional status decline in older patients with breast and colorectal cancer after cancer treatment: A prospective cohort study. *Journal of Geriatric Oncology*, *8*(3), 176-184.

van Heinsbergen, M., Maas, H., Bessems, S., Vogelaar, J., Nijhuis, P., Keijzer-Bors, L., van Liempd, A., & Janssen-Heijnen, M. (2019). Follow-up after surgical treatment in older patients with colorectal cancer: The evaluation of emerging health problems and quality of life after implementation of a standardized shared-care model. *Journal of Geriatric Oncology*, *10*(1), 126-131.

Volanen, S. M., Suominen, S., Lahelma, E., Koskenvuo, M., & Silventoinen, K. (2007). Negative life events and stability of sense of coherence: A five-year follow-up study of Finnish women and men. *Scandinavian Journal of Psychology*, *48*(5), 433-441.

Walsh, J., Harrison, J. D., Young, J. M., Butow, P. N., Solomon, M. J., & Masya, L. (2010). What are the current barriers to effective cancer care coordination? A qualitative study. *BMC Health Services Research*, *10*(132), 1-9.

World Health Organization.. (2020). *WHO report on cancer: setting priorities, investing wisely and providing care for all* (9240001298). World Health Organization.

Williams, G. R., Pisu, M., Rocque, G. B., Williams, C. P., Taylor, R. A., Kvale, E. A., Partridge, E. E., Bhatia, S., & Kenzik, K. M. (2019). Unmet social support needs among older adults with cancer. *Cancer*, *125*(3), 473-481.

Yvonne Feilzer, M. (2010). Doing mixed methods research pragmatically: Implications for the rediscovery of pragmatism as a research paradigm. *Journal of Mixed Methods Research*, *4*(1), 6-16.

Zalon, M. L. (2004). Correlates of recovery among older adults after major abdominal surgery. *Nursing Research*, *53*(2), 99-106.

Part II

List of papers

Paper I

Eriksen, K. S., Husebø, S. I. E., Kørner, H., & Lode, K. (2021). Experiences of recovery from colorectal cancer surgery after hospital discharge among the oldest old: A qualitative study. *Nordic Journal of Nursing Research*, *41*(3), 140-148.

Paper II

Eriksen, K. S., Lode, K., Husebø, S. I. E., & Kørner, H. (2022). Exploring variables affecting sense of coherence and social support in recovery after colorectal cancer surgery among the oldest old. *Geriatric Nursing*, *47*, 81-86.

Paper III

Eriksen, K. S., Husebø, S. I. E., Kørner, H., & Lode, K. (2023) Long-term recovery after colorectal cancer surgery among the old: an interview study. Accepted for publication in *Cancer Nursing*.

Paper I

Nordic Journal of Nursing Research

Article

Nordic Journal of Nursing Research
0(0) 1–9

DOI: 10.1177/2057158521994451
journals.sagepub.com/home/njn
SAGE

Experiences of recovery from colorectal cancer surgery after hospital discharge among the oldest old: A qualitative study

Kristina Sundt Eriksen[1,2], Sissel Iren Eikeland Husebø[2,4], Hartwig Kørner[2,5] and Kirsten Lode[1,3]

Abstract

Colorectal cancer affects a large number of people aged ≥80 years. Little is known about how they manage after discharge from hospital. The aim of this study was to explore the experiences of individuals aged ≥80 years recovering from surgery for colorectal cancer, and the challenges they may encounter after discharge from hospital. Data were collected between January and March 2016 through in-depth interviews with ten participants approximately one month after surgery. Inductive thematic analysis was employed to analyse the data. The COREQ checklist was used in reporting this study. Two themes were identified: *Managing the recovery from CRC surgery,* and *Insufficient follow-up from the healthcare services after CRC surgery.* The findings indicate that older people treated for colorectal cancer manage surprisingly well after discharge despite challenges in their recovery; however, there are seemingly areas of improvement in their follow-up healthcare.

Keywords

colorectal cancer, experience, older people, postoperative recovery

Accepted: 25 January 2021

Colorectal cancer (CRC) is one of the most frequent malignant diseases worldwide with approximately 3.5 million people affected annually, including a large number of patients aged ≥80 years.[1] Surgery is the mainstay for cure, occasionally together with neoadjuvant therapy, and may sometimes involve the creation of either temporary or permanent stoma.[2,3] During and after treatment, disturbing symptoms can occur caused by the treatment itself or the cancer, and older people are particularly susceptible.[2,4] As the proportion of older people in Western populations is growing, the prevalence of CRC survivors is expected to rise during the coming decades.[3] Furthermore, according to national guidelines in Norway, the postsurgical care of patients aged ≥80 years after curative CRC surgery is determined individually outside of systematic follow-up programmes,[5] resulting in limited knowledge of their recovery process. Greater knowledge about the recovery process of older CRC survivors in primary healthcare is essential for facilitating optimal recovery after discharge.

Because of the advances in diagnosis and treatment in addition to greater public awareness, more people are living with cancer as a chronic condition. It is estimated that 40% of cancer survivors in Norway are people aged ≥80 years. Most people in this age group have at least one chronic condition and are susceptible to age-related impairment of cognitive and physical function[6] in addition to the impact of the cancer treatment. The members of this heterogeneous group range from individuals with good health to those with increased vulnerability in terms of treatment and complications.[7] A study from 2019 showed that postoperative complications such as anastomosic leak, delirium and septicaemia occurred in a third of older people surgically treated for CRC.[8] Half of older patients reported a decrease in physical functioning after surgical treatment for CRC.[9] Nevertheless, Devon, Urbach and McLeod[10] found that 78% of older CRC surgery patients returned home after discharge. Nearly half of the older patients were in need of care when discharged

---

[1] Department of Research, Stavanger University Hospital, Stavanger, Norway
[2] Department of Gastrointestinal Surgery, Stavanger University Hospital, Stavanger, Norway
[3] Department of Caring and Ethics, Faculty of Health Sciences, University of Stavanger, Stavanger, Norway
[4] Department of Quality and Health Technology, Faculty of Health Sciences, University of Stavanger, Stavanger, Norway
[5] Department of Clinical Medicine, University of Bergen, Bergen, Norway

Corresponding author:
Kristina Sundt Eriksen, Department of Research, Stavanger University Hospital, Gerd-Ragna Bloch Thorsens Gate 8, 4011 Stavanger, Norway.
Email: kristina.sundt.eriksen@sus.no

from hospital compared with their younger counterparts, where only 20% required assistance.[11] Younger people treated for CRC received homecare nursing, while older people treated for CRC also needed assistance with household tasks and care from multiple professions.[10] Nearly half of all CRC survivors were found to have unmet supportive care needs after discharge.[12] In their study, Samuelson et al. pointed out the lack of knowledge about the oldest old with CRC.[13] They found incomplete information and confusion regarding which section of the healthcare service was responsible for follow-up.[13] Hence, the knowledge regarding older patients' experience of recovery after discharge from hospital is limited. How older people treated for CRC experience challenges after discharge is little explored and understood. The aim of this study was to explore the experiences of individuals aged $\geq$80 years recovering from surgery for CRC and the challenges they may encounter after discharge from hospital.

Method and design

This study employed an exploratory qualitative design[14] as a qualitative inductive approach was considered appropriate for exploring older individuals' experience of postsurgical recovery.[15] The study adhered to the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist[16] (see online supplementary material, file 1).

Participants and recruitment

The participants were recruited from a gastrointestinal surgical department in Western Norway. Purposive sampling was used to obtain maximum variation regarding type of cancer, functional status and gender to capture a wide range of experiences.[17] The inclusion criteria were elective curative resections for colorectal cancer stage I-III and age $\geq$80 years. Exclusion criteria were cognitive impairments and being unable to speak and read Norwegian. A member of the healthcare personnel not affiliated to the project identified and recruited eligible patients during admission for surgery and provided them with written and verbal information regarding the study. Patients who considered participating gave permission to transfer their contact information to the researchers. The first author contacted the individuals in question to provide more verbal information, including information pertaining to their rights as participants, to obtain consent and to arrange an appointment for the interview one month after surgery. No relationship was established between the researcher and the participants prior to study commencement. Although 12 participants were recruited, the medical condition of two participants deteriorated, resulting in cancellation of their interviews. The final number of participants interviewed was thus ten. One week before the interview, the participants received a phone call from the first author to confirm the appointment.

Data collection

Data were collected by the first author (KSE) from January to March 2016 through individual in-depth interviews. The interview guide was developed by the research group based on the research objective and relevant research[18–21] (see online supplementary material, file 2).

Nine of the interviews took place one month after recruitment, while one was conducted after two months. The duration of the interviews ranged from 48–80 minutes and all interviews took place in the participants' homes. During two of the interviews a spouse was present in the room but did not participate. The interviewer presented her clinical and academic background before the interview started. The opening question was 'How did you experience coming home from the hospital?' Follow-up questions were posed to gain a deeper understanding of the participants' statements. The interviewer made field notes to navigate through the interview, but the notes were not included in the analysis. The first interview functioned as a pilot, but as no major changes were necessary it was therefore included in the data analysis.

Data analysis

All interviews were recorded and transcribed verbatim. The audiotape was then compared to the transcripts to ensure accuracy. The transcripts were returned to one participant on request, which resulted in no comment or correction. The empirical data were analysed in accordance with thematic analysis by Braun and Clarke,[22] a semantic analysis that identifies and provides a rich description of patterns across the dataset. The analysis consists of six phases: 1) Familiarizing oneself with the dataset, 2) Generating initial codes, 3) Searching for themes, 4) Reviewing themes, 5) Defining and naming themes, 6) Producing the report.

A research team consisting of the first author (KSE), second author (SIEH) and last author (KL) conducted the analysis. Two of the researchers (SIEH and KL) had experience of qualitative research methods and worked as academics, while the first author (KSE) was a doctoral fellow at a university. At the beginning of each phase a team meeting was held to develop and maintain a shared understanding of the dataset, coding, themes and the next phase of the analysis. Subsequently, KSE conducted the analysis accordingly.

In phase one, the transcripts were subjected to repeated reading to become familiar with the width and depth of the dataset and ideas for coding. In phase two, the initial codes were generated and systematically ordered into a coding manual linked to the appurtenant data extract. In the third phase, codes and the corresponding data extract were sorted into initial themes in a new document grounded in patterns in the dataset. A preliminary thematic map was generated to provide a visual impression of the findings and inherent relationships.[22] In phase four, all data extracts were re-read to ensure a consistent pattern within the different themes. Two themes were downgraded to sub-themes, two themes were reorganized to attain heterogeneity and one theme was removed. The themes were systematically ordered into new documents and revisions were subsequently conducted in the thematic map. In phase five, the names of every theme and sub-theme were refined and adjusted to capture their essence. The findings were written down and the refinement of the themes was again critically assessed so that, together, the themes told the tale of the dataset as a whole.[22]

Ethical considerations

The study was approved by the Regional Committee for medical and health research ethics (REK Vest 2015/1500) and the hospital. Eligible participants received verbal and written information about their right to decline participation without any repercussions; that participation was of a voluntary nature thus they could withdraw from the study at any time and that all information they provided would be treated confidentially. Written informed consent was obtained from each participant before enrolment in the study.

Results

The participants were equally distributed between males and females and aged between 80 and 85 years. Seven out of ten had colon cancer and four received a stoma. To further characterize the participants: one received neo-adjuvant treatment. Four were diagnosed with an unrelated disease during the presurgical examination; one was sufficiently covered with new medication, and two received further examination after the CRC surgery and recovery. Two had additional surgery, one before and one after the CRC surgery. Additionally, one was re-admitted shortly after returning home due to a serious postsurgical complication that required a lengthy hospital stay. A majority managed without a mobility aid, lived in urban areas and four lived with a spouse, while the rest lived alone. Participant characteristics are presented in Table 1.

Table 1. Characteristics of the participants, $n = 10$.

Characteristics	n
Age,	
Median (range)	82 (80–85)
Gender	
Female	5
Male	5
Marital status	
Married	4
Single/widowed/divorced	6
Children	
Yes	9
No	1
Location of cancer	
Colon	7
Rectum	3
Mobility aid preoperatively	
Yes	2
No	8
Creation of a stoma	4
Weeks between surgery and interview	
Mean	5

n: number.

At the beginning of the interviews, the participants reported that their recovery from CRC went quite well and described few challenges in their daily life. However, during the interviews a more detailed story emerged about situations that had been difficult to handle. Two themes were identified through the analysis: *Managing the recovery from CRC surgery* and *Insufficient follow-up from the healthcare services after CRC surgery* based on four and three sub-themes respectively (see Table 2).

Managing the recovery from CRC surgery

This theme describes how the older participants experienced the recovery process, how they coped and which resources they used to manage. An overall impression was that they exhibited an inherent resilience gained through life experience in the way they coped with the challenges of cancer and recovery. This theme consisted of the following sub-themes: *Coping with the cancer diagnosis, CRC and treatment-related problems, Social network and healthcare services ameliorate transition from hospital to home* and *Stoma is an extra burden.*

Coping with the cancer diagnosis. As already mentioned, in the beginning of the interviews some participants expressed that they handled the CRC diagnosis surprisingly well and considered CRC a consequence of being old. When describing physical as well as psychological challenges such as sleep deprivation, anxiety or insecurity regarding their recovery, they seemed to downplay them by minimizing the experience. One participant expressed 'I asked for sleep medication because I do not sleep well . . . I get thoughts, I think about having had cancer, am I more inclined to get it again? . . . But it does not bother me, no, no way' (P2). The participants stated that everything was fine, there was little they could not deal with and some instead focused on the positive aspects of the challenging situation. A few participants avoided talking with others about the cancer, altered bowel movements or physical problems in their pelvic area. Others described avoiding thinking about the cancer and recovery altogether. By ending a statement with a small laugh, they downplayed what they had just said by reducing the impact of the burdens experienced, like the following participant 'The cancer operation itself was terribly painful (laughter)' (P11). Some described having accepted the situation and were prepared for unavoidable discomfort after surgery as one participant stated 'I do not have any pain, of course you can feel it from time to time, it is unavoidable, but not more than you can expect when people cut into you' (P1). Several had experience of cancer due to a previous cancer diagnosis themselves or for their acquaintances. This personal experience with cancer was described as

Table 2. Overview of themes and sub-themes.

Theme	Sub-theme
Managing the recovery from CRC surgery	• Coping with the cancer diagnosis • CRC and treatment-related problems • Social network and healthcare services ameliorate transition from hospital to home • Stoma is an extra burden
Insufficient follow-up from the healthcare services after CRC surgery	• Lack of information can make it more complicated to take care of oneself • The strain of follow-up care • Lack of continuity of care

CRC: colorectal cancer.

reducing the likelihood of being overwhelmed by the diagnosis:

> I have had cancer myself and my husband died of it, so I am familiar with it. When I got breast cancer just three years after my husband died, I thought it was a bit much … Had I not been familiar with cancer … I might have lost my balance … (P7)

Time to the one-month postsurgical consultation for clinical assessment and disclosure of the histopathological result was described as a period with a fluctuating feeling of insecurity ‘It is always at the back of my mind, has it metastasized or not?’ (P6). However, once informed of a favourable prognosis, uncertainties regarding the cancer were replaced by feelings of being blessed, thus enabling them to continue with their lives.

CRC and treatment-related problems. As the interviews proceeded, the participants provided more detailed descriptions of the problems they experienced such as pain, fatigue, altered bowel function, decline in physical functioning, decreased appetite, urinary retention and infections. There were variations in how the severity of the problems affected each individual’s recovery. For some, the problems were an afterthought articulated in a fact-based manner, while for others they permeated the interviews and were expressed emotionally, but with hope of improvement. Those participants who underwent additional treatment such as neoadjuvant radiation or multiple surgery experienced the most complications and naturally described more challenges in recovery. A participant illustrated in a resigned manner how fatigue limited the activities of daily living:

> I just do not have the energy. I have enough problems just walking up the stairs to the second floor. I practically have to use the banisters to pull myself up … I cannot do anything like before … (P8)

Additionally, a few participants expressed feelings of uncertainty about what to expect in terms of symptoms and what was normal, especially with regard to pain levels and physical function. For some, the surgery resulted in changes in daily life related to mobility, which could mean depending on other people’s help. Several participants described the healing of the surgical wound and reduced physical functioning or energy as obstacles to remaining independent with regard to self-care and housework ‘… they [rubbish bags] are too heavy so she [wife] has to carry them, so that I don’t have to’ (P12). Their independence was visible in the way they handled themselves and coped with their challenges. Some described how they persevered by changing their behaviour to handle their recovery ‘Doing laundry, I did that yesterday and I cleaned the bathroom another day. I do not do everything at once as I did before [the surgery]’ (P5).

Social network and healthcare services ameliorate transition from hospital to home. The need for support varied between the participants and changed during their recovery process. Social networks and healthcare services were important resources for managing daily life and challenges after CRC surgery. A short stay in a nursing home or family members staying with them when they returned home from the hospital provided necessary safety and predictability, something that is important for older persons going through major life changes. One participant described how she required a nursing home stay to give her the support she needed to feel safe after hospital discharge:

> The second day after the surgery they came and asked me if I had thought about going home. ‘No’ I said, ‘I will not go home before I get a place at [name of nursing home]’. That is what I said … I felt safe where I was. I did not have the courage to live alone in my own house. (P7)

Assistance from healthcare professionals with self-care at home was necessary for nutrition and safety for a short period, while the need for patient education and assistance with stoma care continued for a longer time. Some participants expressed worries about relying on others’ help because they did not want to be a burden. While insisting on being as self-reliant as possible, they were aware that help was available if needed and a few had contact information for relevant healthcare services. However, others experienced the transition from hospital to home as not demanding, although several obtained personal alarms connected to the homecare services as a precaution. Some required help with ordinary daily household tasks, while others needed assistance with medication, medical equipment and arranging medical appointments: 'Everything we have to purchase … my wife handles. Everything for the stoma and such, she [daughter] arranges and she doses the medication I have to take as there is a lot' (P6). Interestingly, those participants who received assistance from their social network or the homecare services reported that it did not hinder their independence or constitute an invasion of privacy, but provided a sense of security. Help from family and friends was appreciated for minor tasks but when the need for help became comprehensive, it could make them feel as if they were a burden to others: 'I cannot expect my neighbours to take care of me, you cannot do that because then you will lose their friendship' (P7).

Stoma is an extra burden. Having a stoma increased the challenges the participants encountered after returning home. They described difficulties finding suitable equipment and all of them experienced leakage. Furthermore, reactions to the stoma varied from avoidance to acceptance. One participant described with disgust how she recently reacted to the stoma during stoma care 'Then I saw the stoma and you know what, I almost vomited' (P4). The need for stoma care from the homecare services varied from dependency to independence. In addition, they had to be creative in learning how to manage and find a 'new normal'. Some described having to eat at specific times to prevent bowel movements when socializing and they had to spend most of their time at home to avoid embarrassing situations. One participant reported experiencing stoma leakage at night and used towels tucked around the stomach to contain the outflow 'The towel takes the brunt (laughter) because I just fasten it lightly around [stomach]. They are old towels that I am not worried about and can easily throw away' (P1). Due to the stoma one of the participants did not feel safe being away from the house for too long:

> That's how I act now . . . I never go out without having (my stoma) cared for and emptied . . . I feel that when I'm clean and empty I can take an hour and then return home, because then I am safe. (P4)

The experiences of participants with stomas differed from those of the other interviewees because receiving a stoma impaired them from returning to everyday life as it was before the CRC surgery. Their interviews generally entailed more descriptions about lack of equipment and information when they needed it and embarrassment about stoma leakage. Some participants adapted quickly while others needed more time and support.

Insufficient follow-up from the healthcare services after CRC surgery

This theme presents the experiences of several participants who suddenly became responsible for their own follow-up care after having been discharged from the hospital shortly after surgery. There was a feeling of disconnectedness from the healthcare system, where their social network often had to bridge the gap. This theme consisted of the following sub-themes: *Lack of information can make it more complicated to take care of oneself, The strain of follow-up care* and *Lack of continuity of care.*

Lack of information can make it more complicated to take care of oneself. Lack of information was a continuous problem and led to worries and unanswered questions regarding, for example, nutritional issues and stoma care. One participant recounted the difference between the expectation based on a presurgical information letter from the hospital and the reality: 'It was not what was promised in the letter I received that I was going to get some [stoma] education and learn to wash and care for it' (P11). This lack of information culminated in the participants having to find things out for themselves, resulting in poor compliance with new medication and nutritional regimens, and distressing circumstances around stoma care. One participant received contradictory information that could have led to complications such as the development of a hernia or wound rupture and having to endure prolonged correctional treatment:

> I asked the nurses (homecare services) – Do you think I can start exercising again? – Yes, of course you can. Then I thought that I should ask the doctor and it turned out that this was wrong. I should take it easy, I am not even allowed to lift a grocery bag. (P4)

When they needed help, some had trouble contacting healthcare personnel, resulting in extra insecurity in the recovery process. One participant disclosed how the promised nutritional education never took place: '. . . she did not show up! In the commotion of returning home from the hospital I did not get her name. . .' (P3). However, when mistakes occurred, the participants did not blame the healthcare services. They made excuses and expressed understanding about the working conditions and limited availability of resources in the healthcare services.

The strain of follow-up care. The participants had to take responsibility for all follow-up requirements. One participant explained how she had to make an appointment in her general practitioner's (GP) office to get a blood test done, which had to be coordinated with the time of her consultation at the hospital: 'I was at the GP's office. I only saw the nurse; she was to take a blood sample to send to the hospital so that they would have the result by my follow-up appointment …' (P1). This entailed organizing and coordinating various follow-up appointments and the logistics involved. Some participants described doing this without modern technology such as apps, the internet or phones, which made access to the healthcare service more complicated. Several participants mentioned seeking medical advice from healthcare personnel outside their healthcare service who they perceived as more accessible. One participant described how she, while worried about her surgical wound, contacted other persons instead of going to the GP because it was hard to get an appointment and because of the time delay before receiving the necessary medical aid:

> I asked if she [husband's homecare nurse] could take a look at the [surgical] wound and tell me what she thought. Having to walk to the GP's office to arrange a consultation and then having to walk back again for the appointment 14 days later, I only wanted them to look. I did not expect them to do anything about it, I just wanted them to check that it was all right. (P10)

In contrast, one participant excitedly described how she found information about a healthcare centre abroad and applied on her iPad. Furthermore, many of the participants mentioned other unrelated health treatments and follow-up obligations that they had to coordinate with the CRC follow-up care. Some described this as a multifaceted undertaking that could be quite exhausting, and several had to receive help from others to arrange and attend the follow-up appointments.

Lack of continuity of care. When returning home from hospital some of the participants received assistance from multiple homecare services personnel who were often under time pressure. One participant narrated an experience with a member of the homecare staff that she had appreciated because he took the time to talk to her and make her feel safe: 'He gave me so much, I felt safe and it means a lot. The others are very kind but they have so little time . . .' (P4). In addition, several participants were appointed a new GP, before or during the trajectory of cancer treatment. This resulted in an often-unfamiliar GP at a time when their GP was supposed to be the link between the patient and necessary healthcare services. Only a few had consulted their GP within the month after surgery, with appointments often initiated by the hospital. During one interview, a participant wondered why GPs were involved at all:

> . . . Sometimes one thinks to oneself that one could just as well go straight to the hospital . . . why the GP? I wonder, because I do not talk to her [GP] myself. (P4)

It became evident that some of the participants perceived assistance from healthcare personnel who they scarcely knew as obstacles to continuity of care. As a consequence, participants did not feel able to rely on the healthcare service for help to arrange follow-up appointments, thus passing on the responsibility to family members instead.

Discussion

The aim of this study was to explore the experiences of individuals aged ≥ 80 years recovering from surgery for CRC and possible challenges they may encounter after discharge from hospital. As previously mentioned, the participants started the interviews by describing how well they had managed, but during the course of the interviews the challenges became more obvious. Our findings suggest that older individuals treated for CRC varied in their perception of how they managed everyday life after discharge from the hospital. These findings are in accordance with a previous study on coping with the psychological stress of a cancer diagnosis that showed that older people are less psychologically affected by the diagnosis than younger people.[23] However, the study did not discuss the mechanisms behind those findings. The findings in the present study revealed that having the perspective that illness naturally accompanies old age, as well as experiences with cancer, reduced their concern. Our findings were in contrast to a study on older breast cancer patients, where experiences of cancer in others left the participants in fear of recurrence, disfigurement and side effects.[24] In his psychosocial developmental theory, Erikson[25] describes that during a lifetime people experience various life phases dominated by different challenges. In late adulthood people start to experience growing old, characterized by different forms of deterioration. In addition, they encounter personal losses and are faced with the reality of an unavoidable death. Our impression was that the participants' advanced age, long life experience and knowledge influenced their perceptions. In our study, the participants' descriptions of problems and complications were mostly physical. However, some psychological and social challenges were expressed, although the participants stated that they had not consulted family or healthcare personnel about these worries and insecurities. Jorgensen et al.[18] suggest that physical complications could be a manifestation of underreported psychological problems due to the participants' attitudes towards 'unmentionable' issues. The participants in our study downplayed the challenges they faced by laughing after mentioning them. This can be understood as a coping strategy or buffer to downplay difficult topics or to avoid becoming a burden[19,20,26] and the coping mechanism has been reported in relation to cancer diagnosis in other studies.[27]

In the present study, some participants expressed feelings of insecurity regarding what to expect in terms of symptoms when they returned home. Their lack of information and knowledge could hinder their ability to manage self-care, despite being in a situation where it was expected that they assume responsibility for their own health.[28] Receiving written or verbal information is insufficient if the recipients do not understand it and are left uncertain and insecure.[13] The need for information might differ between younger and older CRC patients because of their different perspectives and knowledge regarding cancer and its treatment.[29] A way of giving them a sense of control is to include them in the discharge planning process.[21] However, no such collaboration was described in our findings, nor in another (Norwegian) study by Dyrstad et al. who studied older patients' participation in admission and discharge from hospital.[30] After discharge the GP is responsible for assisting patients with their follow-up. However, only a few of the participants in our study had consulted their GP after discharge. A previous study found that GPs were more involved in the diagnostic process and less in follow-up.[19] When challenges did occur, patients reported uncertainty about whom to contact in the primary or specialist healthcare service. Additionally, GPs and other healthcare personnel in the primary healthcare service lacked experience of CRC.[13,19] To meet the demand for a holistic approach to ensure continuity of care, a specialist nurse-led model for follow-up care was reported to be useful, as nurses are more accessible and have considerable knowledge about living with CRC.[31]

The participants in this study experienced various complications. The recovery period was short and uncomplicated for some, while others had to overcome several challenges. A plausible reason for this variation could be that the surgical complications and recovery are dependent on the actual tumour location.[32] We found that the older participants who had a stoma due to the cancer treatment experienced different problems and one can question whether patients with colon and rectal cancer should be studied separately. Research on CRC survivors shows that complications occur, but our study of older persons treated for CRC revealed a more comprehensive set of complications.[33] However, it must be taken into account that older people's complex health condition entails a higher risk of complications after discharge compared to their younger counterparts.[34] Another possible reason for the variation in our study is that there may be a greater difference in physical and psychological functioning among older patients that increases the risk of surgical complications. Several studies have confirmed that frail older people treated for CRC are especially vulnerable.[8,35–37] However, this study found that family was a particularly important resource for managing recovery and vulnerability. The support and care provided by family members was repeatedly described throughout the findings due to their important role after discharge from hospital. Our findings suggest that support from social networks and public services ranged from occasional practical help with everyday tasks to more medically related issues such as stoma care and continuous assistance with the activities of daily living. Although assistance from one's social network can be a necessity at all ages,[38–40] older persons' need for a social network as a source of security seems to surpass that of their younger counterparts. In our study, these issues were often taken care of by family members but also friends and healthcare personnel. However, Dyrstad et al.[30] found there was no routine for involving older patients' next of kin in the discharge decision-making and family members were not mentioned in the discharge process. Important relatives were often involved at the last minute and received inadequate information, despite the fact that they had to assume a great deal of responsibility after discharge.[40]

Methodological considerations

A methodological strength of this study is the possibility to explore in depth the experience of recovery and possible challenges faced by older people treated for CRC. However, this approach cannot be generalized to all older people treated for CRC. The sample was selected for maximum variation, but we have probably not included the most troubled individuals. Furthermore, the sample consisted of ten participants, which can be considered small. However, the interviews were rich with data, and saturation was believed to be achieved. A further strength of the study was that the researchers endeavoured to ensure trustworthy data by having the first author conduct the data collection to minimize the risk of inconsistency. Additionally, the authors conducted the analysis as a research team and critically discussed each step in the analysis process. Team meetings were held to discuss the generated codes and the content of each theme and sub-theme was rearranged throughout the analysis process. In this process, the authors provided various interpretations of the analysis to ensure the credibility of the results. Quantitative longitudinal studies with a larger sample size should be performed to further explore the symptom burden, coping ability and perceived social support experienced by older people during their recovery from CRC surgery to better determine the need for improved follow-up care.

Conclusion

This study of people aged $\geq$80 years who underwent curative resections for CRC shows that when they return home they cope remarkably well considering the challenges they face. However, the findings suggest that they downplay their needs and burdens. Healthcare personnel must be aware of this when interacting with this group of patients. Our study indicates that older patients often need help from their social networks for their aftercare and that GPs are scarcely involved. There is a need for recognition of the fact that older individuals treated for CRC constitute a unique group whose current follow-up care from the primary healthcare services seemingly does not address their care needs.

Author contributions

Study design: KSE, SIEH, HK, KL; data collection: KSE; data analysis: KSE, SIEH, KL and manuscript preparation: KSE, SIEH, HK, KL.

Acknowledgements

The authors would like to convey their gratitude to the participants for telling their stories.

Declaration of conflicting interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

ORCID iD

Kristina Sundt Eriksen https://orcid.org/0000-0001-7255-9768

Supplemental material

Supplemental material for this article is available online.

References

1. Wild CP, Stewart BW and Wild C. *World cancer report 2014*. Geneva, Switzerland: World Health Organization, 2014.
2. 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: 195–200.
3. Anaya DA, Becker NS and Abraham NS. Global graying, colorectal cancer and liver metastasis: new implications for surgical management. *Crit Rev Oncol/Hematol* 2011; 77: 100–108.
4. Pezaro C and Jefford M. Early stage bowel cancer: follow up and survivorship. *Aust Fam Physician* 2009; 38: 205.
5. 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, 2019.
6. Aldwin CM, Igarashi H, Gilmer DF, et al. *Health, illness, and optimal aging: biological and psychosocial perspectives*. New York: Springer Publishing Company, 2017.
7. Kristjansson SR, Nesbakken A, Jordhøy MS, et al. Comprehensive geriatric assessment can predict complications in elderly patients after elective surgery for colorectal cancer: a prospective observational cohort study. *Crit Rev Oncol/Hematol* 2010; 76: 208–217.
8. Samuelsson KS, Egenvall M, Klarin I, et al. Preoperative geriatric assessment and follow-up of patients older than 75 years undergoing elective surgery for suspected colorectal cancer. *J Geriatr Oncol* 2019; 10: 709–715.
9. van Abbema D, van Vuuren A, van den Berkmortel F, et al. Functional status decline in older patients with breast and colorectal cancer after cancer treatment: a prospective cohort study. *J Geriatr Oncol* 2017; 8: 176–184.
10. Devon KM, Urbach DR and McLeod RS. Postoperative disposition and health services use in elderly patients undergoing colorectal cancer surgery: a population-based study. *Surgery* 2011; 149: 705–712.
11. 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: 695–701.
12. Harrison J, Young J, Auld S, et al. Quantifying postdischarge unmet supportive care needs of people with colorectal cancer: a clinical audit 1. *Colorectal Dis* 2011; 13: 1400–1406.
13. Samuelsson KS, Egenvall M, Klarin I, et al. 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: e1580–e1588.
14. Sim J and Wright C. *Research in health care: concepts, designs and methods*. Cheltenham: Nelson Thornes, 2000.
15. Polit DF and Beck CT. *Nursing research: generating and assessing evidence for nursing practice*. Philadelphia: Lippincott Williams & Wilkins, 2008.
16. Tong A, Sainsbury P and Craig J. Consolidated Criteria for Reporting Qualitative Research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007; 19: 349–357.
17. Patton MQ. Two decades of developments in qualitative inquiry: a personal, experiential perspective. *Qual Soc Work* 2002; 1: 261–283.
18. Jorgensen ML, Young JM, Harrison JD, et al. Unmet supportive care needs in colorectal cancer: differences by age. *Support Care Cancer* 2012; 20: 1275–1281.
19. Browne S, Dowie A, Mitchell ED, et al. Patients' needs following colorectal cancer diagnosis: where does primary care fit in? *Br J Gen Pract* 2011; 61: e692–e699.
20. Beech N, Arber A and Faithfull S. Restoring a sense of wellness following colorectal cancer: a grounded theory. *J Adv Nurs* 2012; 68: 1134–1144.
21. Lithner M, Klefsgard R, Johansson J, et al. The significance of information after discharge for colorectal cancer surgery: a qualitative study. *BMC Nurs* 2015; 14: 36.
22. Braun V and Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006; 3: 77–101.
23. Hernández R, Calderon C, Carmona-Bayonas A, et al. Differences in coping strategies among young adults and the elderly with cancer. *Psychogeriatrics* 2019; 19: 426–434.
24. Pieters HC, Heilemann MV, Grant M, et al. Older women's reflections on accessing care across their breast cancer trajectory: navigating beyond the triple barriers. *Oncol Nurs Forum* 2011; 38: 175–85.
25. Erikson EH and Erikson JM. *The life cycle completed (extended version)*. New York: WW Norton & Company, 1998.
26. Beach WA and Prickett E. Laughter, humor, and cancer: delicate moments and poignant interactional circumstances. *Health Commun* 2017; 32: 791–802.
27. Senden C, Vandecasteele T, Vandenberghe E, et al. The interaction between lived experiences of older patients and their family caregivers confronted with a cancer diagnosis and treatment: a qualitative study. *Int J Nurs Stud* 2015; 52: 197–206.
28. Norlyk A and Harder I. Recovering at home: participating in a fast-track colon cancer surgery programme. *Nurs Inq* 2011; 18: 165–173.
29. Greene MG and Adelman RD. Physician–older patient communication about cancer. *Patient Educ Couns* 2003; 50: 55–60.
30. Dyrstad DN, Laugaland KA and Storm M. An observational study of older patients' participation in hospital admission and discharge: exploring patient and next of kin perspectives. *J Clin Nurs* 2015; 24: 1693–1706.
31. Brown C, Constance K, Bédard D, et al. Colorectal surgery patients' pain status, activities, satisfaction, and beliefs about pain and pain management. *Pain Manag Nurs* 2013; 14: 184–192.
32. Jakobsson J, Idvall E and Wann-Hansson C. Patient-reported recovery after enhanced colorectal cancer surgery: a longitudinal six-month follow-up study. *Int J Colorectal Dis* 2014; 29: 989–998.
33. Fiscon V, Portale G, Frigo F, et al. Laparoscopic resection of colorectal cancer: matched comparison in elderly and younger patients. *Tech Coloproctol* 2010; 14: 323–327.

34. Nielsen LM, Gregersen Østergaard L, Maribo T, et al. Returning to everyday life after discharge from a short-stay unit at the Emergency Department: a qualitative study of elderly patients' experiences. *Int J Qual Stud Health Well-being* 2019; 14: 1563428.
35. 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: 1542–1547.
36. Ommundsen N, Wyller TB, Nesbakken A, et al. Frailty is an independent predictor of survival in older patients with colorectal cancer. *Oncologist* 2014; 19: 1268.
37. Fagard K, Leonard S, Deschodt M, et al. The impact of frailty on postoperative outcomes in individuals aged 65 and over undergoing elective surgery for colorectal cancer: a systematic review. *J Geriatr Oncol* 2016; 7: 479–491.
38. Blazeby J, Soulsby M, Winstone K, et al. A qualitative evaluation of patients' experiences of an enhanced recovery programme for colorectal cancer. *Colorectal Dis* 2010; 12: e236–e242.
39. Jakobsson J, Idvall E and Kumlien C. The lived experience of recovery during the first 6 months after colorectal cancer surgery. *J Clin Nurs* 2017; 26: 4498–4505.
40. Ohlsson-Nevo E, Andershed B, Nilsson U, et al. Life is back to normal and yet not: partners' and patient's experiences of life of the first year after colorectal cancer surgery. *J Clin Nurs* 2012; 21: 555–563.

Paper II

Geriatric Nursing 47 (2022) 81–86

Contents lists available at ScienceDirect

Geriatric Nursing

journal homepage: www.gnjournal.com

Exploring variables affecting sense of coherence and social support in recovery after colorectal cancer surgery among the oldest old

Kristina Sundt Eriksen, RN, MSc[a,b,c,*], Kirsten Lode, RN, PhD[a,d],
Sissel Iren Eikeland Husebø, RN, PhD[c,e], Hartwig Kørner, MD, PhD[c,f]

[a] *Department of Research, Stavanger University Hospital, Stavanger, Norway*
[b] *Faculty of Health Sciences, University of Stavanger, Stavanger, Norway*
[c] *Department of Gastrointestinal Surgery, Stavanger University Hospital, Stavanger, Norway*
[d] *Department of Caring and Ethics, Faculty of Health Sciences, University of Stavanger, Stavanger, Norway*
[e] *Department of Quality and Health Technology, Faculty of Health Sciences, University of Stavanger, Stavanger, Norway*
[f] *Department of Clinical Medicine, University of Bergen, Bergen, Norway*

ARTICLE INFO

Article history:
Received 28 April 2022
Received in revised form 15 June 2022
Accepted 16 June 2022
Available online xxx

Keywords:
Colorectal cancer
Cross-sectional survey
Older people
Postoperative recovery
Sense of coherence
Social support

ABSTRACT

Objective: To explore the associations between sense of coherence, perceived social support, and demographic and clinical characteristics among survivors ≥80 years treated for curable colorectal cancer.
Methods: This exploratory, cross-sectional survey investigates 56 individuals surgically treated for stage I-III colorectal cancer between one and five years prior. Statistical analysis permitted exploration of associations between sense of coherence, perceived social support, and demographic- and clinical variables.
Results: Lower sense of coherence was associated with higher age, limitations in physical function, and the need for homecare nursing. Lower perceived social support was associated with re-admission, higher age at time of surgery, and male gender. No correlations were found between sense of coherence and perceived social support.
Conclusion: The results are important for healthcare professionals to consider when dealing with older people who underwent surgery for colorectal cancer, especially in the discharge process to facilitate optimal follow-up care and recovery.

Introduction

Colorectal cancer (CRC) is the third leading cancer worldwide with approximately 1.9 million people affected annually.[1] CRC is a disease of older people; median age at diagnosis is 72 years in Norway.[2] With increased life expectancy, CRC prevalence will rise in the coming decades. Surgery is the cornerstone of cure and left untreated CRC is a fatal disease accompanied by complications and suffering.[3] In Norway, the post-operative care for patients ≥80 years after curative CRC surgery is determined individually rather than by means of systematic follow-up programs.[4] An excessive post-operative mortality rate among older CRC patients was observed after the first post-operative year, although it has slightly decreased recently due to improvements in surgical techniques and enhanced operative care.[3] Furthermore, older CRC patients are particularly at risk of post-operative complications, delayed recovery, and re-admissions.[5,6] Two thirds of older cancer patients report unmet social support needs after discharge[7] with CRC patients reporting even lower social support levels than other cancer types.[8] The main reasons for support after hospital discharge among older CRC patients are to sustain rehabilitation, provide practical assistance at home, wound care, stoma care, and safety.[9,10] An important resource in recovery is support from family and friends.[10] After the first post-operative year the survival rate among older CRC patients approximately equals that of the non-diseased population,[11] indicating a more stable phase in the recovery. However, reduced physical function and symptom burden can continue to affect recovery, everyday life, and coping capacity.[12,13] Older individuals constitute a heterogeneous population with great variety in health status, comorbidity, coping capacity, social support, as well as functional and cognitive impairment.[14,15] Recovery from CRC surgery in older individuals varies between being manageable and strenuous, requiring individual ways to cope with postoperative challenges in daily life.

The Salutogenesis theory has been proposed by Antonovski as a way to explore coping capacity[16] in older CRC patients. This theory introduced the term *sense of coherence* (SOC), i.e., an individual health

---

[*] Corresponding author at: Department of Research, Stavanger University Hospital, Gerd-Ragna Bloch Thorsens gate 8, 4011 Stavanger, Norway.
E-mail address: kristina.sundt.eriksen@sus.no (K.S. Eriksen).

https://doi.org/10.1016/j.gerinurse.2022.06.008
0197-4572/$ – see front matter

promoting resource, that determines how the individual manages stress.[17] A strong SOC involves the following aspects: 1) Situational awareness where diagnosis, treatment, and impairments are comprehensible; 2) Stress is perceived as manageable due to sufficient internal and external resources; and 3) Life is perceived as meaningful despite the cancer diagnosis and challenges in recovery.[16] Research shows that high SOC levels protect against negative health outcomes in an older general population.[18] Antonovsky believed that SOC develops through life experience and stabilizes in adulthood.[16] Major life events and professional interventions have been shown to alter individuals' SOC; however, this has not been explored in older patients after CRC treatment.[19,20]

Factors that affect coping capacity are important for facilitating a better return to optimal function after surgery. The salutogenesis approach may be useful for revealing factors that affect recovery.[16] Knowledge of the influence of demographic and clinical variables and the role of social support on coping capacity in older people surgically treated for CRC is limited. The present paper aims to 1) explore associations between SOC and demographic variables (gender, age, marital status, and living situation) and clinical variables (recipient of homecare nursing, function status, cancer site, severe postoperative complications, and readmissions), 2) explore perceived social support in association with demographic and clinical variables, and 3) test the hypothesis that high levels of perceived social support correlate with a high SOC score.

Material and methods

This study is an exploratory, cross-sectional analysis of survey data from patients ≥80 years at least one year after surgical treatment for CRC. To ensure quality reporting the study applied the Strengthening the Reporting of Observational studies in Epidemiology (STROBE) checklist for cross-sectional studies.[21] (see Appendix S1).

Participants and procedures

The participants were recruited from a hospital that provides surgical service to a population of 370,000 inhabitants in Norway. Inclusion criteria were patients surgically treated for stage I-III CRC between one and five years prior to the study who were ≥80 years at the time of surgery. Exclusion criteria were inability to understand and speak Norwegian and cognitive impairment. Patients matching the inclusion criteria were identified through a screening of the electronic patient record system. Invitations to participate in the study were sent to 120 eligible participants by mail in 2020 with detailed information about the study, a questionnaire, a consent form, and a reply envelope. The first author contacted patients who had consented to make an appointment for data collection through a telephone interview. Afterwards, clinical data were collected from patient records. Ten participants returned the questionnaire without the signed consent form. Consequently, data from medical records could not be retrieved for them. After three months, a reminder was sent to non-responders. One patient consented to participate in the study but was unable to conduct the survey by phone or return the survey by mail and was thus excluded. The Regional Ethics Committee of Western Norway (REK vest 2017/1739) approved the study.

Measurements

Demographic variables such as gender, age, marital status, cohabitation, and recipient of homecare nursing were collected. Clinical variables on comorbidity, tumor characteristics, and treatment were collected from electronic medical records. Physical function was assessed by the Eastern Cooperative Oncology Group (ECOG) scale of Performance Status.[22] Postoperative complications were graded according to the Accordion Severity Grading system.[23]

The Sense of coherence scale (SOC-13) is a 13-item questionnaire that measures patients' capacity to cope by assessing how they handle stress and remain healthy. The SOC-13 consists of the following domains: manageability (four items), comprehensibility (five items), and meaningfulness (four items) with a 7-point Likert scale. The total score ranges from 13 to 91 points, where a higher score indicates a stronger SOC.[16] As recommended by the author, the questionnaire is presented in one sum score.[17] The questionnaire has been validated with high internal consistency, assessed by Cronbach's α test.[24] It has been translated into numerous languages and found to be applicable across many cultures,[24] thus effective in an older Norwegian population.[25-27] Internal consistency of the SOC-13 in the present sample was acceptable (Cronbach's $\alpha = 0.83$).

The Medical Outcomes Study- Social Support Survey (MOS-SSS) is a 19-item questionnaire that captures how often various types of support were perceived to be available.[28] The MOS-SSS assesses four subscales: emotional/informational support (eight items), tangible support (four items), affectionate support (three items), and positive social interaction (four items), in addition to one extra item. A higher score indicates a greater level of perceived social support. The questionnaire is rated on a 5-point Likert scale. The questionnaire has been used to assess the perceived social support levels of cancer patients, including those with CRC.[7,29-31] The internal consistency of the MOS-SSS and the separate subscales in the present sample was acceptable (Cronbach's $\alpha > 0.83$).

Statistical analysis

Frequencies (n) and proportions described demographic and clinical data. The Chi- square test of independence was used to assess the difference between participants and non-participants. Non- normality of the data was revealed by the Kolmogorov–Smirnov test, resulting in non-parametric analysis being performed. The Mann-Witney U was applied to analyse associations between categorical demographic and clinical variables with SOC-13 and MOS-SSS. Spearman's correlation (rho; ρ) assessed relationships between ranked variables of demographic and clinical data with SOC-13 and MOS-SSS, with and without controlling for confounding variables (ρ_p) namely; age group, cancer site, gender, time since surgery, and physical function, with the exeption of variables already in the analysis. 95% confidence intervals (95% CI) for Spearman's correlation were based on the bootstrap method with 1,000 samples. Spearman's correlation was evaluated according to Cohen's guidelines; 0.10-0.29 were interpreted as a small correlation, 0.30-0.49 represented a medium correlation, 0.50 and above were interpreted as a strong correlation.[32]

One participant did not complete the MOS-SSS questionnaire and three had one missing item in the questionnaire. Another participant did not complete the SOC-13 and two had missing items in the SOC-13, where one had one missing item and the other had two missing items. Missing items were handled according to the specific analysis; pairwise for Mann-Witney U and Spearman's correlation and listwise for Spearman's partial correlation. Analyses were performed using IBM® SPSS® Statistics, version 26. A two-tailed p-value of less than 0.05 was considered statistically significant.

Results

Demographic and clinical characteristics

Of 120 eligible patients, 56 (47%) responded to the questionnaire (Fig. 1). Reasons for non- participation were not obtained. No significant differences were found between responders and non- responders regarding gender, age, cancer site, or time since surgery.

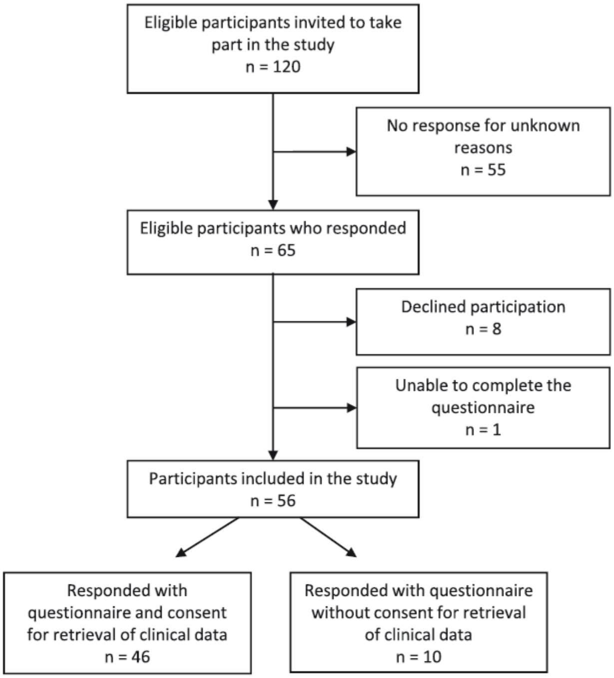


Fig. 1. Flow chart of the inclusion process.

Table 1 presents the participants' demographic and clinical characteristics. The median age of participants at the time of surgery was 83 years (range 80-90 years) and 86 years (range 82-94 years) when answering the questionnaire, a median time of 3 years (range 1-5) after treatment. Median length of hospital stay was 5 days (range 2-19 days). The most common severe postoperative complications were rectal bleeding, wound dehiscence, and acute kidney failure. The most common causes of readmission to hospital were deteriorated general condition, infection or acute abdominal pain, often within the first two weeks up to two months after discharge. Two participants were readmitted due to the need for surgical intervention.

Relationship between the Sense of coherence scale and demographic- and clinical variables

Median SOC scores were similar for male and female participants, indicating they had similar coping capacity after surgery, see Table 2. Participants who currently received homecare nursing had significantly lower SOC scores than participants who did not receive homecare nursing, see Table 3. The SOC score had a moderate inverse correlation with age at surgery (ρ = -.33, 95% CI = -.058, -.558, p = .025), although after checking for confounding variables the significance disappeared (ρ_p = -.25, p = .110). ECOG was found to have a strong correlation with SOC score (ρ = -.53, 95% CI = -.298, -.714, $p < .001$) also after correcting for confounding variables (ρ_p = -.47, p = .002) i.e., participants with a high level of physical function had a significantly higher SOC score than participants reporting lower ECOG. No associations were found between the SOC score and the occurrence of severe complications, readmissions, or the other clinical or demographical variables.

Relationship between the Medical Outcome Study-Social Support Survey and demographic and clinical variables

The score of the MOS-SSS subscale 'affectionate support' was significantly lower in males compared to females (p = .010), see Table 2. As a group, females reported both higher total MOS-SSS and on all MOS-SSS subscales, indicating that females perceived all aspects of social support to be more available; however, not all findings were significant, see Table 2. A significantly higher level of 'affectionate support' and 'social interaction' were observed in participants who did not currently receive homecare nursing, see Table 3. Participants readmitted after discharge experienced lower levels of 'tangible support' compared to those not readmitted (median score 14.0 vs. 20.0, p = .008). Perceived 'tangible support' had a moderate inverse correlation with age at surgery (ρ = -.30, 95% CI = .009, -.572, p = .045) and

Table 1
Demographic and clinical characteristics of participants.

		N (%)	*Missing*
Gender	Male	17 (31.5)	2
	Female	37 (68.5)	
Age group	80-86	25 (54.3)	10
	87+	21 (45.7)	
Marital status	Single/ Widowed	34 (63.0)	2
	Married/Partners	20 (37.0)	
Cohabiting		24 (44.4)	2
Current recipient of homecare nursing		18 (34.0)	3
ECOG	Grade 0	9 (16.7)	2
	Grade 1	35 (64.8)	
	Grade 2	6 (11.1)	
	Grade 3	4 (7.4)	
Co-morbidity	Cardio-vascular disease	33 (71.7)	10
	Respiratory disease	7 (15.2)	
Cancer site	Colon	41 (89.1)	10
	Rectum	5 (10.9)	
TNM	Stadium 0	1 (2.3)	13
	Stadium I	12 (27.9)	
	Stadium II	16 (37.2)	
	Stadium III	14 (32.6)	
ASA	2	21 (45.7)	10
	3	25 (54.3)	
Type of surgery	Right hemicolectomy	28 (60.9)	10
	Left hemicolectomy, sigmoid- or subtotal colectomy	12 (26.1)	
	Rectal resection or amputations	6 (13.0)	
Postoperative complications	Mild and moderate: Grade 1 and 2	22 (47.8)	10
	Severe: Grade 3, 4, and 5	9 (19.5)	
Re-admissions		15 (32.6)	10
Presence of stoma	Never had a stoma	36 (78.3)	10
	Permanent stoma	5 (10.9)	
	Temporary stoma, reversed	5 (10.9)	

Abbreviations: ECOG, Eastern Cooperative Oncology Group performance status; TNM, Tumor-node-metastasis classification; ASA, American Society of Anesthesiologists grading system.

Note: Three participants underwent surgery for B-cell lymphoma, a tubulo-villous adenoma and hyperplastic polyps, thus not included in TNM classification. Postsurgical complications according to Accordion Severity Classification of Postoperative Complications.

current age (ρ = -.34, 95% CI = -.034, -.641, p = .021) also after correcting for confounding variables for age at surgery (ρ_p = -.33, p = .035) and current age (ρ_p = -.41, p = .007). There were no other significant findings in perceived social support between participants who experienced or did not experience severe postoperative complications.

Relationship between the Medical Outcome Study-Social Support Survey and Sense of coherence scale

No significant correlations were found between SOC score and total MOS-SSS score or the MOS-SSS sub-scale scores.

Table 2
Differences by gender in reported outcome scores on Sense of coherence and Medical Outcome Study-Social Support Survey.

	Males Median	Females Median	Total Median	Range	*P*
Sense of coherence Scale	67.5	69.0	68.0	34-91	0.831
Medical Outcome Study-Social Support Survey	70.0	84.0	79.0	32-95	0.115
Emotional/informational support	25.5	34.0	33.0	8-40	0.240
Tangible support	15.0	18.5	17.0	4-20	0.442
Affectionate support	11.0	15.0	12.0	3-15	0.010*
Positive social interaction	11.0	12.0	12.0	5-15	0.073

*$p < 0.05$.

Discussion

This study explored associations between SOC, perceived level of social support, and demographic and clinical characteristics among survivors ≥80 years treated for CRC. We found SOC to be associated with age at time of surgery, physical functioning, and current receipt of homecare nursing. Re-admission and gender were associated with perceived social support and/or its sub-scales. Our study found a negative correlation between age at surgery and SOC score. Antonovsky proposed that a major life event could result in a decline in SOC and people with an originally lower SOC were more susceptible to further decline.[16] People with decreased SOC were especially vulnerable to challenging situations, resulting in less effective coping strategies and an increased mortality risk.[33,34] Furthermore, according to Baltes and Smith,[35] one must be realistic about the aging process and its effects on individuals and their coping capacity. A part of the aging process is an escalation in decreasing control of bodily function, cognition, and relationships in addition to increased comorbidities.[35,36] Thus, the morbidity associated with the surgical trauma may have a greater impact on individuals with a higher age.[6] Because of the moderate inverse correlation between SOC score and the variable “age at surgery” found in our study, one can suggest that surgery becomes a particularly challenging life event with increasing age and further hypothesize that the oldest CRC patients may benefit from individualized pre- and postsurgical interventions with health promotion efforts.

Our study found that a high SOC score was associated with high physical function in terms of the ECOG classification, in accordance with other studies of older participants,[18,37,38] although none within the context of recovery after CRC surgery. This association of high functional level in everyday life and a higher coping capacity underlines the need to address functional capacities during the treatment trajectory of older patients with CRC, and to focus on older people’s wishes to maintain their activities in daily life after surgery.[39]

A decline in physical function among older people surgically treated for CRC has been shown to influence independent living,[10] which is in line with our finding of a significant association between lower SOC and the domain of “currently receiving homecare nursing”. It is reasonable to assume that receiving homecare nursing is a proxy for declining physical function and loss of ability to perform activities of daily living. However, according to Antonovsky,[16] external resources like homecare nursing should compensate for the lack of internal resources, and thus not be expressed in terms of lower SOC in this group. Therefore, one can question whether healthcare services target the symptom but do not solve the underlying cause. The possible associations between lower levels of SOC and the need for healthcare resources require further investigation.

We found that a lack of perceived tangible support was associated with unplanned hospital re-admission. This finding is in accordance with the study of a general surgical population by Graham.[40] In addition to observation and identification of changes in the older CRC patients during recovery, close supervision and support can alleviate everyday challenges. Inadequate care at home after discharge can lead to deterioration in a person’s health that can require re-admission. In our study, 15 participants were re-admitted, several due to deterioration in their general condition. Further research is warranted to explore whether interventions with increased social support after discharge could reduce the number of unplanned re-admissions in this population. However, some post-operative complications after CRC surgery can appear after discharge such as anastomotic leakage or abscess. Because of the timespan between re-admission and data collection we cannot exclude that the decline in social support may have occurred over time. Other researchers have discussed if the decline in support during recovery could be an expression of prolonged burden experienced by caregivers.[8,31] Family

Table 3
Differences in participant reported outcome on Sense of coherence and Medical Outcome Study-Social Support Survey between participants currently receiving and not receiving homecare nursing.

	Receiving homecare nursing Median	Not receiving homecare nursing Median	U	Z	P
Sense of coherence	62.0	73.5	411.5	2.90	0.004*
Medical Outcome Study - Social Support Survey	70.0	82.0	319.0	1.59	0.111
Emotional/informational support	30.5	33.5	312.5	0.84	0.396
Tangible support	16.0	19.0	377.5	1.41	0.156
Affectionate support	10.0	15.0	403.0	2.59	0.009*
Positive social interaction	9.0	13.0	486.5	3.52	<0.001*

*p <0.05.

members are expected to support the older CRC patient practically and emotionally during the cancer trajectory and recovery. This task can be exhausting and become a burden, thus leading to decreased support over time. Furthermore, we found that female gender scored higher on each subscale of the MOS-SSS. The relationship between gender and perceived social support among older CRC patients has been little explored, and with contradictory results.[8,31]

This study found no correlation between the MOS-SSS and SOC. According to Antonovsky, social support has been presented as an external resource to manage stressful situations, with a clear beneficial relationship between social support and SOC.[16] A quantitative study of Norwegian nursing home residents showed the importance of social support and SOC for health and wellbeing, although no correlation between the two concepts was described.[26] However, social support is a multifaceted concept with different types of measuring tools, an aspect that is beyond the scope of this study.

In addition to SOC, there are several other concepts that try to explain the inherent ability to cope with adversity, such as resilience,[41] hardiness,[42] and self-transcendence.[43] Resilience is the most common concept and entails the ability to "bounce back" despite encountering adversity.[44] SOC and resilience have a high empirical correlation and theoretical overlap.[45] SOC was chosen for this study as it has been used successfully within previous Norwegian cohorts.

Limitations and strengths

The present study is based on data from ≥1 year survivors ≥80 years treated for cure of CRC. Paradoxically, while older patients represent a major proportion of those diagnosed with CRC, most research is directed towards younger age groups. As older patients are generally more vulnerable compared to their younger counterparts, we think it is particularly important to address their ability to cope after major surgery. Our patients were recruited from the catchment area of our instution, which provides surgical service as single institution in a public healthcare setting. The participants represent the older patients who were able to participate in a study using standard tools such as the SOC and MOS-SSS and from this perspective, a 47% response rate can be deemed highly satisfactory. Our study population may be considered to have a reasonable distribution of age, functional status, tumor stage, and tumor location, and that our findings may be applicable to other populations with similar characteristics. However, the limited sample size increases the likelihood of a type II error due to limited statistical power. The participants may represent a selction of the healthiest patients who were probably more inclined to participate. The study was performed at the beginning of the COVID pandemic. Despite the fact that there were alarming rates of infection across the world, only 10,000 COVID-related deaths were registered in Norway out of a population of a little over five million inhabitants at the end of the data collection. Additionally, data collection was performed by phone without any face-to-face interaction between the researcher and the participants. Despite societal lockdown, the restrictions in everyday life were limited compared to other countries. Therefore, the researchers consider the influence of the pandemic on the study as minimal. However, the authors cannot guarantee that the pandemic did not affect inclusion. Some of the eligible participants could have felt overwhelmed by the threat of the virus, and thus felt unable to participate in the study. Patients were included after one and up to five years after CRC surgery, and it is reasonable to assume that recovery after surgery has reached a stable level after 1 year. However, the possible influence of physiological decline in mental and physical functioning due to the aging process is hard to control for in the analysis. Therefore, time since surgery is used as a counfounding variable in the correlation analysis. The ten questionnaires returned without the consent form are included in the study as we consider the act of completing the questionnaire and mailing it back to the researcher as an indication of consent. Further research is needed to explore the moderating effects of variables such as social support on SOC in datasets with a sufficient sample size.

Conclusion

Psychosocial aspects of recovery should receive greater attention when discharging older patients operated for CRC to facilitate optimal recovery and individualized follow-up care for an independent life at home. This study found that age at time of surgery, physical functioning, and need for homecare nursing was associated with coping capacity expressed as SOC. Furthermore, re-admission, age at time of surgery, and gender were associated with perceived social support. Our study found no correlation between SOC and perceived social support or any association between SOC and experienced postoperative complications or re-admission. Despite some limitations, we think that our study adds important knowledge on the ability of patients ≥80 years to cope with their life after major surgery for CRC. Further research is warranted to understand the relationship between psychosocial aspects and functional outcomes after CRC surgery.

Funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Acknowledgments

The authors are very grateful to all individuals who willingly participated in the study. We would also like to covey our gratitude to Anastasia Ushakova for assistance with the statistical analysis.

Supplementary materials

Supplementary material associated with this article can be found in the online version at doi:10.1016/j.gerinurse.2022.06.008.

References

1. WHO. Colorectal cancer.. Cancer today - cancer fact sheets. *World Health Organization*. 2020.
2. Cancer in Norway 2019: Cancer Registry of Norway; 2020. DOI: https://www.kreftregisteret.no/globalassets/cancer-in-norway/2019/cin_report.pdf.
3. Brouwer NP, Heil TC, Rikkert MGO, et al. The gap in postoperative outcome between older and younger patients with stage I-III colorectal cancer has been bridged; results from the Netherlands cancer registry. *Eur J Cancer*. 2019;116:1–9.
4. 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]: The Norwegian Directorate of Health 2020.
5. 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:e525–e536.
6. Fagard K, Casaer J, Wolthuis A, et al. Postoperative complications in individuals aged 70 and over undergoing elective surgery for colorectal cancer. *Colorectal Dis*. 2017;19:O329–O338.
7. Williams GR, Pisu M, Rocque GB, et al. Unmet social support needs among older adults with cancer. *Cancer*. 2019;125:473–481.
8. Eom CS, Shin DW, Kim SY, et al. Impact of perceived social support on the mental health and health-related quality of life in cancer patients: results from a nationwide, multicenter survey in South Korea. *Psychooncology*. 2013;22:1283–1290.
9. 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;261:695–701.
10. 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. *Nordic J Nurs Res*. 2021 2057158521994451.
11. Verweij N, Schiphorst A, Maas H, et al. Colorectal cancer resections in the oldest old between 2011 and 2012 in the Netherlands. *Ann Surg Oncol*. 2016;23:1875–1882.
12. O'Gorman C, Stack J, O'Ceilleachair A, et al. Colorectal cancer survivors: an investigation of symptom burden and influencing factors. *BMC Cancer*. 2018;18:1–10.
13. Rønning B, Wyller TB, Jordhøy MS, et al. Frailty indicators and functional status in older patients after colorectal cancer surgery. *J Geriatric Oncol*. 2014;5:26–32.
14. Kristjansson SR, Nesbakken A, Jordhøy MS, et al. Comprehensive geriatric assessment can predict complications in elderly patients after elective surgery for colorectal cancer: a prospective observational cohort study. *Crit Rev Oncology/hematology*. 2010;76:208–217.
15. Salive ME. Multimorbidity in older adults. *Epidemiol Rev*. 2013;35:75–83.
16. Antonovsky A.*Unraveling the mystery of health: How people manage stress and stay well*: Jossey-bass; 1987.
17. Antonovsky A. *Health, Stress, and Coping: New Perspectives on Mental And Physical Well-Being*. San Francisco: Jossey-Bass; 1979.
18. 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. *The Annals of Family Medicine*. 2016;14:337–343.
19. Sarid O, Berger R, Segal-Engelchin D. The impact of cognitive behavioral interventions on SOC, perceived stress and mood states of nurses. *Procedia-Social and Behavioral Sciences*. 2010;2:928–932.
20. Kähönen K, Näätänen P, Tolvanen A, Salemela-Aro K. Development of sense of coherence during two group interventions. *Scand J Psychol*. 2012;53:523–527.
21. Von Elm E, Altman DG, Egger M, et al. The Strengthening the reporting of observational studies in epidemiology (STROBE) statement: guidelines for reporting observational studies. *Int J Surgery*. 2014;12:1495–1499.
22. Conill C, Verger E, Salamero M. Performance status assessment in cancer patients. *Cancer*. 1990;65:1864–1866.
23. Strasberg SM, Linehan DC, Hawkins WG. The accordion severity grading system of surgical complications. *Ann Surg*. 2009;250:177–186.
24. Eriksson M, Lindström B. Validity of Antonovsky's sense of coherence scale: a systematic review. *J Epidemiol Commun Health*. 2005;59:460–466.
25. Drageset J, Espehaug B, Kirkevold M. The impact of depression and sense of coherence on emotional and social loneliness among nursing home residents without cognitive impairment–a questionnaire survey. *J Clin Nurs*. 2012;21:965–974.
26. 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;46:66–76.
27. Drageset J, Haugan G. Psychometric properties of the Orientation to Life Questionnaire in nursing home residents. *Scand J Caring Sci*. 2016;30:623–630.
28. Sherbourne CD, Stewart AL. The MOS social support survey. *Soc Sci Med*. 1991;32:705–714.
29. Sodergren S, Wheelwright S, Permyakova N, et al. Supportive care needs of patients following treatment for colorectal cancer: risk factors for unmet needs and the association between unmet needs and health-related quality of life—results from the ColoREctal Wellbeing (CREW) study. *J Cancer Survivorship*. 2019;13:899–909.
30. Priede A, Andreu Y, Martínez P, Conchado A, Ruiz-Torres M, González-Blanch C. The factor structure of the Medical Outcomes Study–Social Support Survey: A comparison of different models in a sample of recently diagnosed cancer patients. *J Psychosom Res*. 2018;108:32–38.
31. Haviland J, Sodergren S, Calman L, et al. Social support following diagnosis and treatment for colorectal cancer and associations with health-related quality of life: Results from the UK ColoREctal Wellbeing (CREW) cohort study. *Psychooncology*. 2017;26:2276–2284.
32. Cohen J. *Statistical Power Analysis for the Behavioral Sciences*. 2013.
33. Wainwright N, Surtees P, Welch A, Luben R, Khaw K, Bingham S. Sense of coherence, lifestyle choices and mortality. *J Epidemiol Commun Health*. 2008;62:829–831.
34. Sarenmalm EK, Browall M, Persson LO, Fall-Dickson J, Gaston-Johansson F. Relationship of sense of coherence to stressful events, coping strategies, health status, and quality of life in women with breast cancer. *Psychooncology*. 2013;22:20–27.
35. Baltes PB, Smith J. New frontiers in the future of aging: From successful aging of the young old to the dilemmas of the fourth age. *Gerontology*. 2003;49:123–135.
36. Pitt B. Loss in late life. *BMJ*. 1998;316:1452–1454.
37. Avlund K, Vass M, Hendriksen C. Onset of mobility disability among community-dwelling old men and women. The role of tiredness in daily activities. *Age Ageing*. 2003;32:579–584.
38. Lövheim H, Graneheim UH, Jonsén E, Strandberg G, Lundman B. Changes in sense of coherence in old age - a 5-year follow-up of the Umeå 85+ study. *Scand J Caring Sci*. 2013;27:13–19.
39. Wainwright NW, Surtees PG, Welch AA, Luben RN, Khaw K-T, Bingham SA. Healthy lifestyle choices: could sense of coherence aid health promotion? *J Epidemiol Commun Health*. 2007;61:871–876.
40. Graham LA, Hawn MT, Dasinger EA, et al. Psychosocial determinants of readmission after surgery. *Med Care*. 2021;59:864–871.
41. Masten AS, Best KM, Garmezy N. Resilience and development: contributions from the study of children who overcome adversity. *Dev Psychopathol*. 1990;2:425–444.
42. Kobasa SC. Stressful life events, personality, and health: an inquiry into hardiness. *J Pers Soc Psychol*. 1979;37:1.
43. Reed PG. Toward a nursing theory of self-transcendence: deductive reformulation using developmental theories.*Advances in Nursing Science*1991.
44. Windle G. What is resilience? A review and concept analysis. *Rev Clin Gerontol*. 2011;21:152–169.
45. Lindström B, Eriksson M. Contextualizing salutogenesis and Antonovsky in public health development. *Health Promot Int*. 2006;21:238–244.

Paper III

Title

Long-term recovery after colorectal cancer surgery among the old: a qualitative study

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

Department of Research, Stavanger University Hospital, Stavanger, Norway (Eriksen and Lode)
Department of Gastrointestinal Surgery, Stavanger University Hospital, Stavanger, Norway (Eriksen, Husebø and Kørner)
Faculty of Health Sciences, University of Stavanger, Stavanger, Norway (Eriksen, Lode and Husebø)
Department of Clinical Medicine, University of Bergen, Bergen, Norway (Kørner)

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

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

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

Abstract

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 of age is essential to optimise recovery and follow-up care. Objective: To explore the experiences of persons ≥ 80 years of age during recovery up to two 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 employed to analyse the data. Results: The main theme identified was *Recovery among the old is a complex process*. It indicated that older people operated 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 sub-themes *Individual factors affect colorectal cancer recovery* and *External support systems facilitate and impede colorectal recovery.* Conclusions: 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 optimise recovery when needed.

Long-term recovery after colorectal cancer surgery among the old: a qualitative study

Colorectal cancer (CRC) is the third most frequently diagnosed cancer worldwide in both sexes.[1] Approximately 40% of all CRC patients in Norway are over the age of 80 years.[2] With increasing life expectancy, the number of people newly diagnosed with 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 aged ≥ 80 years to be determined individually outside of systematic follow-up programmes.[3]

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.[4, 5] 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.[6] However, CRC surgery is associated with short- and long-term complications and symptoms that may be particularly bothersome for older patients.[7-9] Physical functioning has been reported to be significantly reduced in older people two years after CRC surgery.[8, 10] Reduced physical function and persistent symptom burden continuously affect recovery, everyday life and coping capacity.[10, 11] Thus, older people are more prone to having delayed recovery compared to their younger counterparts.[12] However, health-related quality of life has been found to have improved already three months post-operatively and be sustained forward compared with preoperative levels.[13] 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 individualised rehabilitation and experience of unmet needs of social support.[14-16] The risk of unmet needs of social support was associated with a high symptom burden.[16]

Despite experiencing challenges shortly after discharge, older people appear to cope and persevere.[15] This may be in accordance with the theory of salutogenesis, i.e., 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).[17] SOC can be seen as a health-promoting resource that measures a person's capacity to cope.[18] Research has shown that SOC correlates with age and physical function in CRC recovery among the old[19] and protects against negative health outcomes in an older general population [20].

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 of age experienced recovery up to two years after curative surgery for CRC.

Methods

This study has an exploratory inductive qualitative design to illuminate patients' experiences of recovery in the first two years after surgery.[21]

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 aged 80 years and older.

Convenience sampling was applied since the participants themselves had to take action and contact the researcher to volunteer to participate.[22] The inclusion criteria were a) having undergone elective curative resections for stage I–III CRC between one and two years prior and b) being ≥ 80 years old at the time of surgery. Exclusion criteria were a) the presence of cognitive impairments and b) 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 that 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, ten agreed to participate. The first seven 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, three 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 six 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 (XXX) in the participants' homes and lasted approximately one and a half hours each. Prior to the interviews, an interview topic guide was developed based on the study's research objective and existing literature[X,X.] (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[23]. 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. The interviewer took field notes to navigate the interview, in addition to helping preserve and explore non-verbal 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.

(Insert table 1)

Data analysis

Data were analysed according to the work on qualitative inductive content analysis by Graneheim and Lundman [24, 25] 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' 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 three steps. The first step began with familiarisation with the transcripts to gain a comprehensive understanding of the extent of the data. The first author then performed a de-contextualisation of the interviews by identifying and dividing the interview transcripts into meaning units. The meaning units were condensed before they were abstracted and labelled 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 de-contextualisation process and making appropriate adjustment to the codes. In the second step, the first author re-contextualised the data material by forming sub-categories based on patterns linking different codes. Patterns across sub-categories were then linked in categories describing the visible patterns in the data.[24] In the third step, the mutual underlying meaning for several categories was interpreted into themes. A new transcript of the analysis with themes, categories, codes and meaning units was distributed to the analysis team. The analysis team then discussed the re-contextualisation, which caused the emergence of a main theme, reducing the other themes to sub-themes based on the interpretation of the underlying meaning of the themes.[24] See Table 2 for a detailed example of the analysis process. The qualitative data analysis software NVivo 12[26] was used to organise the data and support a systematic analysis.

(Insert table 2)

Ethical considerations

Ethical approval was obtained from the Regional Ethics Committee of Western Norway (REK Vest XXXX) as well as from the hospital. Eligible participants were provided with written and oral information about the study and their rights. Prior to 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 three characteristics: credibility, dependability and transferability. This approach was first described by Lincoln and Guba[27] and has been recommended for qualitative content analysis[24]. *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 employed 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 minimise the risk of inconsistency. To ensure *transferability*, a detailed description of the context, participants, recruitment, data collection and analysis are presented. Additionally, comprehensive descriptions of the findings were provided, together with appropriate quotations. The transferability of the results to other cultures may be limited since 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.[28]

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, two had received radiation prior to surgery and six participants received a stoma as a part of the cancer operation (see Table 3 for further details).

(Insert table 3)

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 two sub-themes, each based on two categories (see Table 4).

(Insert 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 health care services promoted recovery by providing support when unmet needs occurred; however, an issue arose when expectations of support and reality were unaligned. This theme consists of two sub-themes, namely *Individual factors affect colorectal cancer recovery* and *External support systems facilitate and impede colorectalcancer recovery*. Each sub-theme is built upon two categories.

Sub-theme 1: Individual factors affect colorectal cancer recovery

This sub-theme 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 participant's 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 health care 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 towards 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 to 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, odour, 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. Afterwards, some participants felt that they had regained their general condition and health, thus considering recovery to be complete. At the same time, the majority of 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, odour, 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 prior 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, 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)

Sub-theme 2: External support systems facilitate and impede colorectal cancer recovery

This sub-theme 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 fulfil and provide for themselves. However, problems in recovery could arise when they experienced discrepancies between their expectations of home care nursing and reality.

Category: Health care services and social networks 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. Additionally, 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 health care 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: Health care 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 health care activities.

Discrepancy sometimes occurred between the expected and provided support, resulting in unmet needs in recovery. Throughout recovery, several participants described needing support from health care services. A few participants reported that their requests for assistance or aids were denied by the health care service, such as a request for assistance with food preparation because of reduced energy or instalment 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 health care service and the primary health care 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 health care service regarding the participant's ability and capacity to manage became visible. There was an expectation from health care services that the participant could use e-health services when communicating with some health care 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, while others had no follow-up. One participant wanted more follow-up as a reassurance of the cancer being gone, while another trusted the doctor's judgement regarding what was needed in terms of follow-up.

In a few instances, the general practitioner took the initiative to organise 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 organised 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 health care 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, gynaecologist…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 the first two 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 health care 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[29] and possibly have a profound impact on functional outcomes.[30, 31] Furthermore, receiving a stoma can be a specific burden related to CRC treatment. Having a stoma and being > 85 years of age increased the probability of experiencing a higher frequency of symptoms up to 2.5 years into recovery.[32]

The participants in the present study were concerned with physical function, symptoms and returning to a normal life beyond one year after surgery. The participants experienced reduced physical function compared to the preoperative status and felt like a burden to others since 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.[10] 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 individualised follow-up care is an important aspect of the cancer trajectory in older cancer patients.[33] Promoting resource-oriented follow-up care could improve their health[18] and ability to manage recovery. This agrees with the theory of salutogenesis. By screening older patients for SOC through the Orientation to Life Questionnaire, health care 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 utilise the person's strength in these. Although no cut-off 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[34] and optimise individual recovery.

Some participants in the present 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.[35] It can be difficult to talk about and impair participation in social life.[36, 37] 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.[14]

This study found that several participants were enlisted in a 5-year follow-up program even though national guidelines do not recommend the systematic follow-up of patients aged 80 years and above but rather encourage them to keep in contact with the general practitioner.[3] Based on the findings of this study, the decision to enrol old patients in the systematic follow-up program should be made on an individual basis as most old patients with metachronous metastases will not be eligible for treatment for 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 organisational responsibility. The participants found the responsibility in terms of health care 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 health care services in lifting this organisational burden. Increased health care utilisation 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 just dealing with their recovery but having to manage other health problems in addition to normalising everyday life.[38] 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 the present 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 the prognostic value of treatment outcomes.[39, 40] 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 five comorbidities, with two emerging after the cancer treatment.[41] 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.[42]

Furthermore, having a supportive network, i.e., family or close friends, was seen to be a vital resource in CRC recovery among the old, concurrent with earlier research.[14, 15, 43, 44] Social support can positively influence an individual's SOC by shaping a perception that can boost the individuals 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.[17, 45] Studies have shown that social support is an important resource for older people to maintain functioning, physical health and quality of life.[46, 47] Our findings show that older patients appreciate help but they were to some degree afraid of becoming a burden.[14, 15] The finding that participants sometimes abstain from asking for help is an aspect that health care 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 evaluated closer to the surgery.[15] 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.[48] 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, behavioural and motivational sense, thus allowing for the application of appropriate resources to manage the situation[18] that could make the cancer trajectory appear less daunting. Patients of higher ages seem to adjust better to cancer[49] and be psychologically less affected.[50] 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 to 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 generalised to all older people recovering from CRC surgery.

The interviews were conducted up to two 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 since 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 health care 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 health care 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 the older person's experience throughout the recovery process and the challenges they encounter and identifying health-promoting resources are essential to optimise follow-up care. Health care 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 optimise 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 health care problems and symptom management should be included in addition to actions to ease organisational responsibility when needed.

Conclusion

Our findings suggest that older people recovering from CRC treatment are a vulnerable group with complex health care conditions that can influence and sometimes hamper their recovery. The older persons' inner strength and support from family and health care 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.

References

1. 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: a cancer journal for clinicians*. 2021;71(3):209-249.

2. Cancer Registry of Norway. *Annual repport for colorectal cancer 2021*. 2022. https://www.kreftregisteret.no/globalassets/publikasjoner-og-rapporter/arsrapporter/publisert-2022/arsrapport-2021-nasjonalt-kvalitetsregister-for-tykk--og-endetarmskreft.pdf

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]*. 2021.

4. 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. *Annals of surgery*. 2015;261(4):695-701.

5. Aldwin CM, Igarashi H, Gilmer DF, Levenson MR. *Health, illness, and optimal aging: Biological and psychosocial perspectives*. 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. *Gerontology and geriatric medicine*. 2017;3:2333721417706299.

7. 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. *Critical Reviews in Oncology/Hematology*. 2008/09/01/ 2008;67(3):229-236. doi:https://doi.org/10.1016/j.critrevonc.2008.03.005

8. 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. *Journal of Geriatric Oncology*. 2018/03/01/ 2018;9(2):102-109. doi:https://doi.org/10.1016/j.jgo.2017.09.005

9. Ommundsen N, Nesbakken A, Wyller TB, et al. Post-discharge complications in frail older patients after surgery for colorectal cancer. *European Journal of Surgical Oncology*. 2018;44(10):1542-1547.

10. Rønning B, Wyller TB, Jordhøy MS, et al. Frailty indicators and functional status in older patients after colorectal cancer surgery. *Journal of geriatric oncology*. 2014;5(1):26-32.

11. 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.

12. 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. *The lancet oncology*. 2012;13(12):e525-e536.

13. 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. *Journal of geriatric oncology*. 2016;7(3):195-200.

14. 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. *Journal of clinical nursing*. 2018;27(7-8):e1580-e1588.

15. 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. *Nordic Journal of Nursing Research*. 2021:2057158521994451.

16. Williams GR, Pisu M, Rocque GB, et al. Unmet social support needs among older adults with cancer. *Cancer*. 2019;125(3):473-481.

17. Antonovsky A. *Unraveling the mystery of health: How people manage stress and stay well*. Jossey-bass; 1987.

18. Antonovsky A. The salutogenic model as a theory to guide health promotion. *Health promotion international*. 1996;11(1):11-18.

19. 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. *Geriatric Nursing*. 2022;47:81-86.

20. 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. *The Annals of Family Medicine*. 2016;14(4):337-343.

21. Sim J, Wright C. *Research in health care: concepts, designs and methods*. Nelson Thornes; 2000.

22. Polit DF, Beck CT. *Nursing research: Generating and assessing evidence for nursing practice- eleventh edition*. Lippincott Williams & Wilkins; 2020.

23. Kvale S, Brinkmann S, Anderssen TM, Rygge J. Det kvalitative forskningsintervju (2. utg.). *Oslo: Gyldendal akademisk*. 2015:50-60.

24. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse education today*. 2004;24(2):105-112.

25. Graneheim UH, Lindgren B-M, Lundman B. Methodological challenges in qualitative content analysis: A discussion paper. *Nurse education today*. 2017;56:29-34.

26. *NVivo Qualitative Data Analysis Software, version 12*. QSR International Pty Ltd; 2018. https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home

27. Lincoln YS. Naturalistic inquiry. *The Blackwell Encyclopedia of Sociology*. 2015;

28. Ponterotto JG. Brief note on the origins, evolution, and meaning of the qualitative research concept thick description. *The qualitative report*. 2006;11(3):538-549.

29. Sav A, McMillan SS, Akosile A. Burden of Treatment among Elderly Patients with Cancer: A Scoping Review. Multidisciplinary Digital Publishing Institute; 2021:612.

30. 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 medical research methodology*. 2017;17(1):1-14.

31. Norlyk A, Harder I. Recovering at home: participating in a fast-track colon cancer surgery programme. *Nursing inquiry*. 2011;18(2):165-173.

32. 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. *Journal of clinical oncology*. 2015;33(6)

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 Expectations*. 2021;24(2):478-490.

34. Dietscher C, Winter U, Pelikan JM. The application of salutogenesis in hospitals. *The handbook of salutogenesis*. 2017:277-298.

35. Reinwalds M, Blixter A, Carlsson E. Living with a resected rectum after rectal cancer surgery—Struggling not to let bowel function control life. *Journal of clinical nursing*. 2018;27(3-4):e623-e634.

36. 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 oncologica*. 2019;58(5):801-810.

37. Norton C. Nurses, bowel continence, stigma, and taboos. *Journal of Wound Ostomy & Continence Nursing*. 2004;31(2):85-94.

38. Sav A, King MA, Whitty JA, et al. Burden of treatment for chronic illness: a concept analysis and review of the literature. *Health Expectations*. 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 treatment reviews*. 2018;64:30-39.

40. 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;356:968-74.

41. Leach CR, Weaver KE, Aziz NM, et al. The complex health profile of long-term cancer survivors: prevalence and predictors of comorbid conditions. *Journal of cancer survivorship*. 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. *International journal of older people nursing*. 2018;13(1):e12172.

43. Jakobsson J, Idvall E, Kumlien C. The lived experience of recovery during the first 6 months after colorectal cancer surgery. *Journal of clinical nursing*. 2017;26(23-24):4498-4505.

44. Stuhlfauth S, Melby L, Hellesø R. Everyday life after colon cancer: the visible and invisible challenges. *Cancer nursing*. 2018;41(6):E48-E57.

45. Wiesmann U, Hannich H-J. A salutogenic analysis of healthy aging in active elderly persons. *Research on 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. *Quality of life Research*. 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. *International Journal of Nursing Studies*. 2009/01/01/ 2009;46(1):66-76. doi:https://doi.org/10.1016/j.ijnurstu.2008.07.005

48. Averill PM, Beck JG. Posttraumatic stress disorder in older adults: a conceptual review. *Journal of Anxiety disorders*. 2000;14(2):133-156.

49. Cohen M, Baziliansky S, Beny A. The association of resilience and age in individuals with colorectal cancer: an exploratory cross-sectional study. *Journal of geriatric oncology*. 2014;5(1):33-39.

50. Hernández R, Calderon C, Carmona-Bayonas A, et al. Differences in coping strategies among young adults and the elderly with cancer. *Psychogeriatrics*. Sep 2019;19(5):426-434. doi:10.1111/psyg.12420

Tables

Table 1. Interview Topic Guide

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	Items	Questions
Significance of the disease in everyday life	Experience of symptoms	Which symptoms have you experienced?
	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 organisation of your follow-up?
	Organization of follow-up	Have you been in contact with health care 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 with your general practitioner about your cancer surgery or recovery?
	Other follow-up arrangements	Have you had contact with other health care personnel after discharge?
	Inclusion of next of kin	Were your next of kin, family or friends involved in communication with health care services? Did they receive any information before discharge or after doctor visits?
	Information	Did you receive information regarding recovery, activity, possible complications, ways to handle symptoms? Did you miss any information in recovery? If yes, could you elaborate?

Examples of clarifying questions: • Can you elaborate? • How did you experience this? • How did this experience make you feel? • Earlier you told me about …. Can you elaborate? • Can you give me an example of this? • How did this affect your everyday life?
Final question: Is there anything you would like to add that we have not talked about and that you think is of importance for your recovery after the CRC operation?

Table 2. An Example of the Analysis Process

Meaning unit	Code	Category	Sub-theme	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	Health care services may create problems in recovery	External support systems facilitate and impede colorectal cancer recovery	Recovery among the old is a complex process

Table 3. Characteristics of the Participants

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, Sub-themes and Categories

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

Appendices

Appendix 1 - Interview guide study 1

Interview guide

Opening question	**How did you experience coming home from hospital?**
Themes	Activities of daily living
	Nutrition
	Bowel function
	Wound healing
	Living situation
	Deficiencies in health care follow-up
	Adverse events/complications
	Contact with healthcare services
	Coping
	Emotional/psychological response

Appendix 2 - Questionnaire study 2

HELSE **STAVANGER**
Stavanger universitetssjukehus

Spørreskjema

Dagliglivet etter tarmkreftoperasjon for personer 80 år og eldre

Veiledning til utfylling av spørreskjemaet

Spørreskjemaet du har foran deg inneholder spørsmål om din livskvalitet, støtte fra sosialt nettverk, opplevelse av sammenheng, informasjon og kommunikasjon fra sykehuset og fysisk funksjon. Det er viktig at du svarer ut fra slik du tenker og føler, og ikke ut fra det du tror vi vil, eller andre synes du bør svare. Det er ingen fasitsvar.

Som avtalt vil en forsker ringe deg slik dere kan fylle ut spørreskjemaet sammen per telefon. Vi er takknemlige for at du tar deg tid til å svare på dette spørreskjemaet. Vi forsikrer om at opplysninger vil bli behandlet på en måte som gjør det umulig å gjenkjenne den enkeltes svar.

På forhånd tusen takk for hjelpen!

Kristina Sundt Eriksen
Stipendiat
Stavanger
Universitetssjukehus

Kirsten Lode
Førsteamanuensis
Stavanger
Universitetssjukehus/
Universitetet i Stavanger

Sissel Eikeland Husebø
Professor
Universitetet i Stavanger/ Stavanger
Universitetssjukehus

Hartwig Kørner
Professor
Stavanger
Universitetssjukehus/
Universitetet i Bergen

Bakgrunnsdata

Sett kryss

01. Hva er nåværende sivilstatus?

Enslig	☐1
Kjæreste	☐2
Samboer	☐3
Gift	☐4
Skilt/ Separert (uten ny partner)	☐5
Enke/ -mann	☐6

02. Hvordan er bosituasjonen din?

Jeg bor alene	☐1
Med samboer/ ektefelle/ partner	☐2
Med barn	☐3
Med venner	☐4
Med søsken	☐5
Offentlig bolig/ institusjon	☐6
Annen type	☐7

03. Har du hjemmesykepleie?

Ja ☐1 → Gå til spørsmål 4

Nei ☐2 → Gå til spørsmål 5

04. Hvor ofte har du hjemmesykepleie?

Daglig	☐1
Ukentlig	☐2
Ved behov	☐3

05. Har du vært i kontakt med lege etter utskrivelse?

Ja ☐1 → Gå til spørsmål 6

Nei ☐2 → Gå til spørsmål 7

06. Hvor ofte har du vært i kontakt med lege etter utskrivelse?

Ukentlig	☐1
Månedlig	☐2
Sjeldnere	☐3

Livskvalitet

En del pasienter opplever av og til at de har noen av følgende symptomer eller problemer. Vær vennlig å angi i hvilken grad du har hatt disse symptomene eller problemene i løpet av **den siste uka**. Sett en ring rundt det tallet som best beskriver din tilstand.

I løpet av den siste uken	**Ikke i det hele tatt**	**Litt**	**En del**	**Svært mye**
07. Har du hatt hyppig vannlating i løpet av dagen?	1	2	3	4
08. Har du hatt hyppig vannlating i løpet av natten?	1	2	3	4
09. Har du hatt ufrivillig vannlating (lekkasje)?	1	2	3	4
10. Har du hatt smerter ved vannlating?	1	2	3	4
11. Har du hatt magesmerter?	1	2	3	4
12. Har du hatt smerter i setet/analområdet /rektum?	1	2	3	4
13. Har du følt deg oppblåst i magen?	1	2	3	4
14. Har du hatt blod i avføringen?	1	2	3	4
15. Har du hatt slim i avføringen?	1	2	3	4
16. Har du vært tørr i munnen?	1	2	3	4
17. Har du mistet hår på grunn av behandling?	1	2	3	4
18. har du hatt problemer med smakssansen?	1	2	3	4

I løpet av den siste uken	**Ikke i det hele tatt**	**Litt**	**En del**	**Svært mye**
19. Har du vært bekymret for din fremtidige helse?	1	2	3	4
20. Har du bekymret deg for økning eller nedgang i vekt?	1	2	3	4
21. Har du følt deg mindre fysisk tiltrekkende på grunn av sykdom eller behandling?	1	2	3	4
22. Har du følt deg mindre kvinnelig/mandig på grunn av sykdommen eller behandlingen?	1	2	3	4
23. Har du vært misfornøyd med kroppen din?	1	2	3	4

24. Har du utlagt tarm (utlagt tykktarm / utlagt tynntarm? (Vennligst sett en ring rundt riktig svar)	Ja	Nei

I løpet av den siste uken	**Ikke i det hele tatt**	**Litt**	**En del**	**Svært mye**
Svar på disse spørsmålene KUN HVIS DU HAR STOMIPOSE, hvis ikke, fortsett nedenfor:				
25. Har du hatt ufrivillig utslipp av luft/flatulens fra stomiposen?	1	2	3	4
26. Har du hatt avføringslekkasje fra stomiposen?	1	2	3	4
27. Har du hatt sår hud rundt stomien?	1	2	3	4
28. Har du måttet bytte pose flere ganger i løpet av dagen?	1	2	3	4
29. Har du måttet bytte pose flere ganger i løpet av natten?	1	2	3	4
30. Har du følt deg flau på grunn av stomien?	1	2	3	4
31. har du hatt problemer med å stelle stomien?	1	2	3	4
Svar på disse spørsmålene KUN HVIS DU IKKE HAR EN STOMIPOSE:				
32. Har du hatt ufrivillig utslipp av luft / flatulens fra endetarmen?	1	2	3	4
33. Har du hatt avføringslekkasje fra endetarmen?	1	2	3	4
34. Har du hatt sår hud rundt endetarmsåpningen?	1	2	3	4
35. har du hatt hyppig avføring i løpet av dagen?	1	2	3	4
36. Har du hatt hyppig avføring i løpet av natten?	1	2	3	4
37. Har du følt deg flau når du har hatt avføring?	1	2	3	4

I løpet av de siste fire ukene:	**Ikke i det hele tatt**	**Litt**	**En del**	**Svært mye**
Bare for menn:				
38. I hvilken grad har du vært interessert i seksualitet?	1	2	3	4
39. I hvilken grad har du hatt problemer med å få eller opprettholde ereksjon?	1	2	3	4
Bare for kvinner:				
40. I hvilken grad har du vært interessert i seksualitet?	1	2	3	4
41. I hvilken grad har du opplevd smerte eller ubehag ved samleie?	1	2	3	4

Støtte fra sosialt nettverk

Mennesker søker sammen for selskap, assistanse eller andre typer støtte. Hvor ofte har du tilgang til følgende typer støtte dersom du har behov for det? (Sett et kryss for hver linje)

Følelsesmessig/informasjonsmessig støtte	*Aldri*	*Sjelden*	*Av og til*	*Som oftest*	*Alltid*
42. Noen du kan stole på vil lytte når du trenger en å snakke med	☐1	☐2	☐3	☐4	☐5
43. Noen som kan gi deg informasjon slik at du bedre forstår en situasjon	☐1	☐2	☐3	☐4	☐5
44. Noen som kan gi deg gode råd i en krisesituasjon	☐1	☐2	☐3	☐4	☐5
45. Noen du kan snakke med om deg selv eller dine problemer	☐1	☐2	☐3	☐4	☐5
46. Noen som du virkelig ønsker råd fra	☐1	☐2	☐3	☐4	☐5
47. Noen du kan dele dine innerste bekymringer og frykt med	☐1	☐2	☐3	☐4	☐5
48. Noen du kan vende deg til for å få hjelp til å takle et personlig problem	☐1	☐2	☐3	☐4	☐5
49. Noen som forstår dine problemer	☐1	☐2	☐3	☐4	☐5
Praktisk støtte					
50. Noen som kan hjelpe deg hvis du ikke kommer deg ut av sengen	☐1	☐2	☐3	☐4	☐5
51. Noen som kan følge deg til legen ved behov	☐1	☐2	☐3	☐4	☐5
52. Noen som kan hjelpe med matlaging hvis du ikke er i stand til å gjøre det selv	☐1	☐2	☐3	☐4	☐5
53. Noen som kan hjelpe med daglige gjøremål hvis du blir syk	☐1	☐2	☐3	☐4	☐5
Kjærlig støtte					
54. Noen som viser deg kjærlighet og hengivenhet	☐1	☐2	☐3	☐4	☐5
55. Noen som du kan elske og få deg til å føle deg ønsket	☐1	☐2	☐3	☐4	☐5
56. Noen som gir deg en klem	☐1	☐2	☐3	☐4	☐5
Positiv sosial samhandling					
57. Noen du kan ha det morsomt sammen med	☐1	☐2	☐3	☐4	☐5
58. Noen du kan slappe av sammen med	☐1	☐2	☐3	☐4	☐5
59. Noen du kan gjøre noe hyggelig sammen med	☐1	☐2	☐3	☐4	☐5
Tilleggs punkt					
60. Noen du kan gjøre ting sammen med slik at du får tankene vekk fra andre ting	☐1	☐2	☐3	☐4	☐5

Opplevelse av sammenheng

Her er en serie spørsmål som omhandler ulike sider ved livet vårt. Hvert spørsmål har 7 svar alternativer. Vennligst kryss av for det tallet som best utrykker det som passer for deg. Tallene 1 og 7 representerer ytterpunktene. Hvis ordene til venstre for rute 1 er rett for deg, setter du et kryss i rute nummer 1. Hvis ordene til høyre for rute 7 er rett for deg, krysser du i rute 7. Hvis du føler noe midt mellom, setter du kryss i den ruten som passer best for deg. **Vennligst sett bare ett kryss for hvert spørsmål.**

61. Opplever du at du ikke bryr deg om det som skjer i omgivelsene dine?

1 2 3 4 5 6 7
Veldig sjeldent eller aldri ☐ ☐ ☐ ☐ ☐ ☐ ☐ Veldig ofte

62. Har du opplevd at du er blitt overrasket over oppførselen til personer du trodde du kjente godt?

1 2 3 4 5 6 7
Det har aldri hendt ☐ ☐ ☐ ☐ ☐ ☐ ☐ Det hender alltid

63. Har det hendt at personer du stoler på har skuffet deg?

1 2 3 4 5 6 7
Det har aldri hendt ☐ ☐ ☐ ☐ ☐ ☐ ☐ Det hender alltid

64. Inntil nå har livet mitt …

1 2 3 4 5 6 7
vært helt uten mål og mening ☐ ☐ ☐ ☐ ☐ ☐ ☐ hatt mål og mening

65. Føler du deg urettferdig behandlet?

1 2 3 4 5 6 7
Veldig ofte ☐ ☐ ☐ ☐ ☐ ☐ ☐ Veldig sjeldent eller aldri

66. Opplever du ofte at du er i en uvant situasjon og at du er usikker på hva du skal gjøre?

1 2 3 4 5 6 7
Veldig ofte ☐ ☐ ☐ ☐ ☐ ☐ ☐ Veldig sjeldent eller aldri

67. Er dine dagligdagse aktiviteter en kilde til …

1 2 3 4 5 6 7
Glede og tilfredsstillelse? ☐ ☐ ☐ ☐ ☐ ☐ ☐ Smerte og kjedsomhet?

68. Har du veldig motstridende tanker og følelser?

1 2 3 4 5 6 7
Veldig ofte ☐ ☐ ☐ ☐ ☐ ☐ ☐ Veldig sjeldent eller aldri

69. Skjer det at du har følelser som du helst ikke vil føle?

1 2 3 4 5 6 7
Veldig ofte ☐ ☐ ☐ ☐ ☐ ☐ ☐ Veldig sjeldent eller aldri

70. Alle mennesker vil kunne føle seg som tapere iblant. Hvor ofte føler du deg slik?

1 2 3 4 5 6 7
Aldri ☐ ☐ ☐ ☐ ☐ ☐ ☐ Veldig ofte

71. Hvor ofte opplever du at du over- eller undervurderer betydningen av noe som skjer?

1 2 3 4 5 6 7
Du over- eller undervurderer det som skjer ☐ ☐ ☐ ☐ ☐ ☐ ☐ Du ser saken i rett sammenheng

72. Hvor ofte føler du at de tingene du gjør i hverdagen er meningsløse?

	1	2	3	4	5	6	7	
Veldig ofte	☐	☐	☐	☐	☐	☐	☐	Veldig sjeldent eller aldri

73. Hvor ofte har du følelser du ikke er sikker på at du kan kontrollere?

	1	2	3	4	5	6	7	
Veldig ofte	☐	☐	☐	☐	☐	☐	☐	Veldig sjeldent eller aldri

Informasjon og kommunikasjon fra sykehuset

	Ikke i det hele tatt	*I liten grad*	*I noen grad*	*I stor grad*	*I svært stor grad*	*Ikke aktuelt*
74. Ble du informert om hvilke plager du kunne få i tiden fremover etter operasjonen?	☐1	☐2	☐3	☐4	☐5	☐6
75. Ble du informert om hva du selv kunne gjøre ved eventuell forverring av din tilstand?	☐1	☐2	☐3	☐4	☐5	☐6
76. Er du fornøyd med den skriftlige informasjonen du fikk fra sykehuset?	☐1	☐2	☐3	☐4	☐5	☐6

Fysisk funksjon

77. Her er fem beskrivelser, hvilken føler du beskriver ditt funksjonsnivå:

I stand til å utføre enhver normal aktivitet uten begrensing	☐1
Ikke i stand til krevende aktivitet, men oppgående og i stand til å utføre lett arbeid	☐2
Oppegående og i stand til all egenpleie, men ikke stand til noe arbeid. Oppe og i bevegelse mer enn 50 % av våken tid	☐3
Bare i stand til begrenset egenpleie, bundet til seng eller stol mer enn 50 % av våken tid	☐4
Helt hjelpetrengende, klarer ikke noen egenpleie, helt bundet til seng eller stol	☐5

Slutt på spørreskjema.

Tusen takk for at du tok deg tid til å svare!

Appendix 3 - Interview topic guide study 3

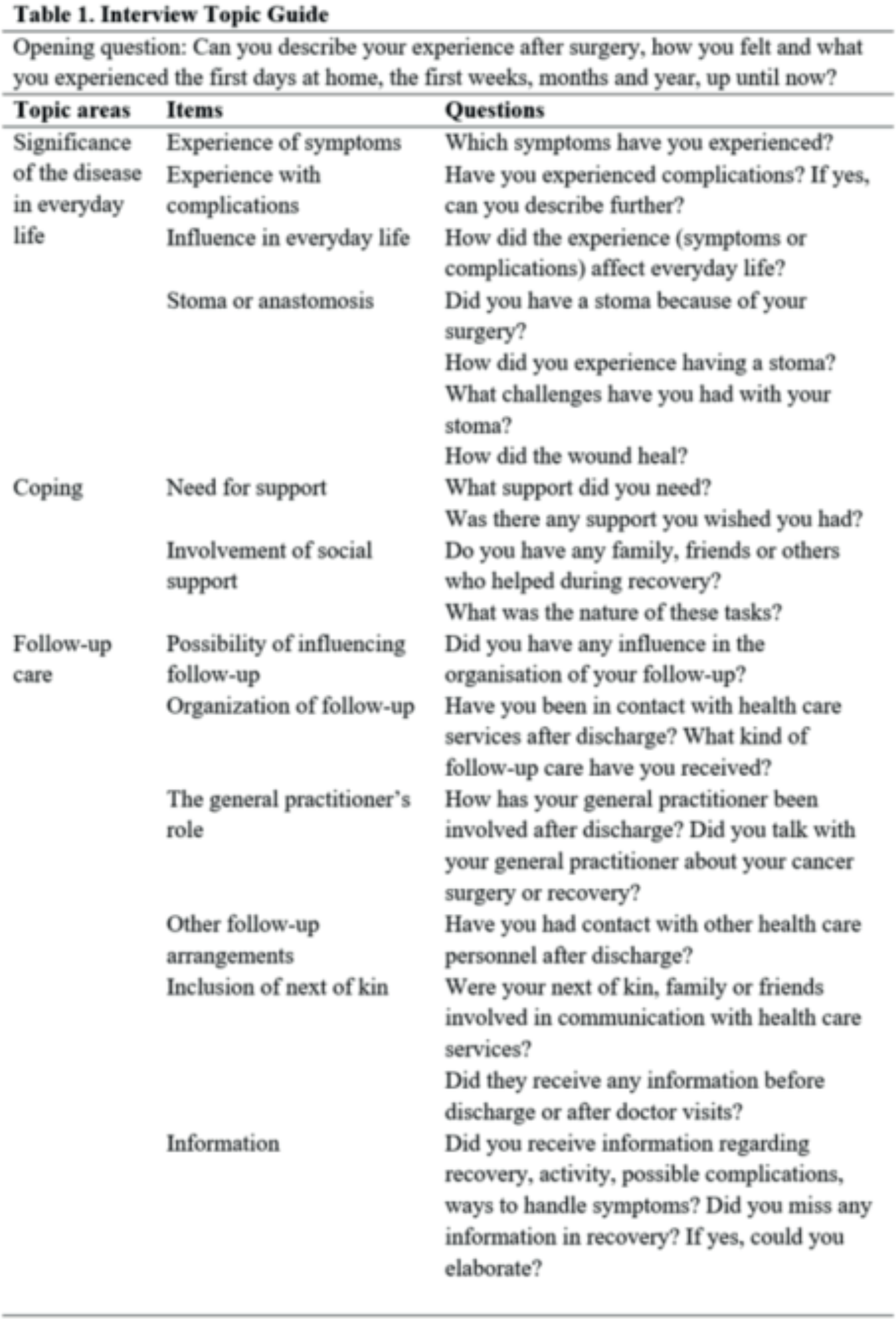
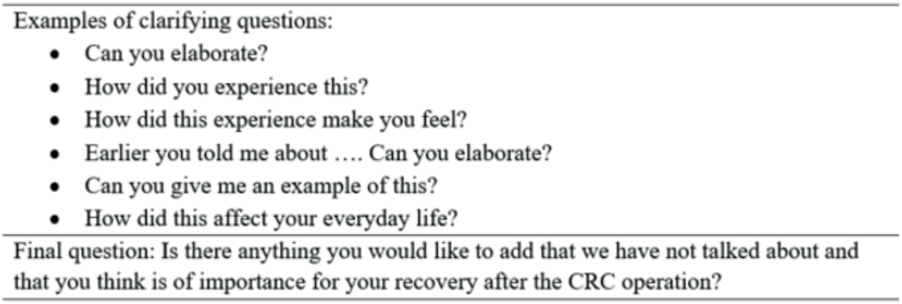


Table 1. Interview Topic Guide

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	Items	Questions
Significance of the disease in everyday life	Experience of symptoms	Which symptoms have you experienced?
	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 organisation of your follow-up?
	Organization of follow-up	Have you been in contact with health care 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 with your general practitioner about your cancer surgery or recovery?
	Other follow-up arrangements	Have you had contact with other health care personnel after discharge?
	Inclusion of next of kin	Were your next of kin, family or friends involved in communication with health care services? Did they receive any information before discharge or after doctor visits?
	Information	Did you receive information regarding recovery, activity, possible complications, ways to handle symptoms? Did you miss any information in recovery? If yes, could you elaborate?

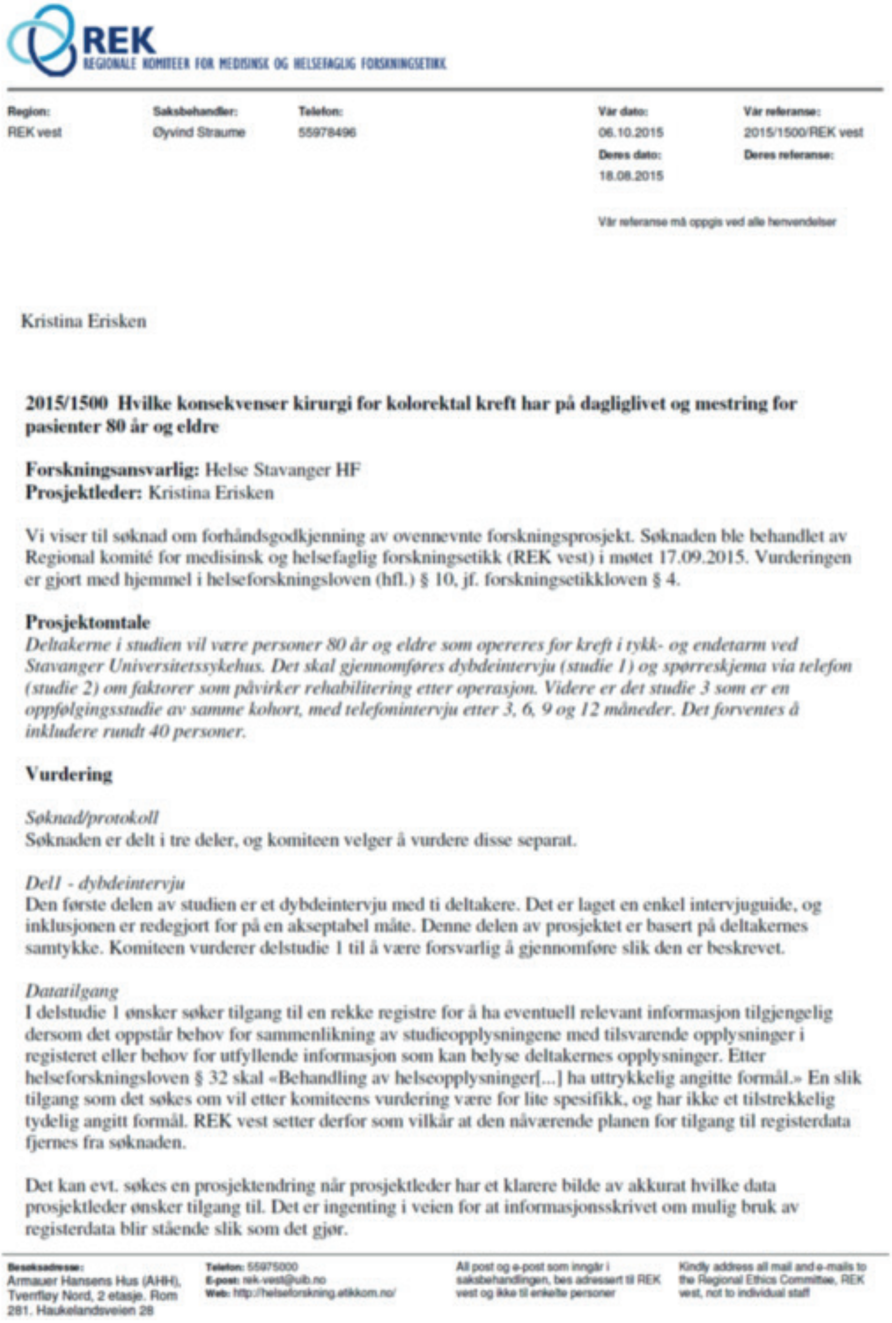


Examples of clarifying questions:

- Can you elaborate?
- How did you experience this?
- How did this experience make you feel?
- Earlier you told me about …. Can you elaborate?
- Can you give me an example of this?
- How did this affect your everyday life?

Final question: Is there anything you would like to add that we have not talked about and that you think is of importance for your recovery after the CRC operation?

Appendix 4 - Ethical approval



REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region: REK vest
Saksbehandler: Øyvind Straume
Telefon: 55978496
Vår dato: 06.10.2015
Vår referanse: 2015/1500/REK vest
Deres dato: 18.08.2015
Deres referanse:

Vår referanse må oppgis ved alle henvendelser

Kristina Erisken

2015/1500 Hvilke konsekvenser kirurgi for kolorektal kreft har på dagliglivet og mestring for pasienter 80 år og eldre

Forskningsansvarlig: Helse Stavanger HF
Prosjektleder: Kristina Erisken

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK vest) i møtet 17.09.2015. Vurderingen er gjort med hjemmel i helseforskningsloven (hfl.) § 10, jf. forskningsetikkloven § 4.

Prosjektomtale
Deltakerne i studien vil være personer 80 år og eldre som opereres for kreft i tykk- og endetarm ved Stavanger Universitetssykehus. Det skal gjennomføres dybdeintervju (studie 1) og spørreskjema via telefon (studie 2) om faktorer som påvirker rehabilitering etter operasjon. Videre er det studie 3 som er en oppfølgingsstudie av samme kohort, med telefonintervju etter 3, 6, 9 og 12 måneder. Det forventes å inkludere rundt 40 personer.

Vurdering

Søknad/protokoll
Søknaden er delt i tre deler, og komiteen velger å vurdere disse separat.

Del1 - dybdeintervju
Den første delen av studien er et dybdeintervju med ti deltakere. Det er laget en enkel intervjuguide, og inklusjonen er redegjort for på en akseptabel måte. Denne delen av prosjektet er basert på deltakernes samtykke. Komiteen vurderer delstudie 1 til å være forsvarlig å gjennomføre slik den er beskrevet.

Datatilgang
I delstudie 1 ønsker søker tilgang til en rekke registre for å ha eventuell relevant informasjon tilgjengelig dersom det oppstår behov for sammenlikning av studieopplysningene med tilsvarende opplysninger i registeret eller behov for utfyllende informasjon som kan belyse deltakernes opplysninger. Etter helseforskningsloven § 32 skal «Behandling av helseopplysninger[...] ha uttrykkelig angitte formål.» En slik tilgang som det søkes om vil etter komiteens vurdering være for lite spesifikk, og har ikke et tilstrekkelig tydelig angitt formål. REK vest setter derfor som vilkår at den nåværende planen for tilgang til registerdata fjernes fra søknaden.

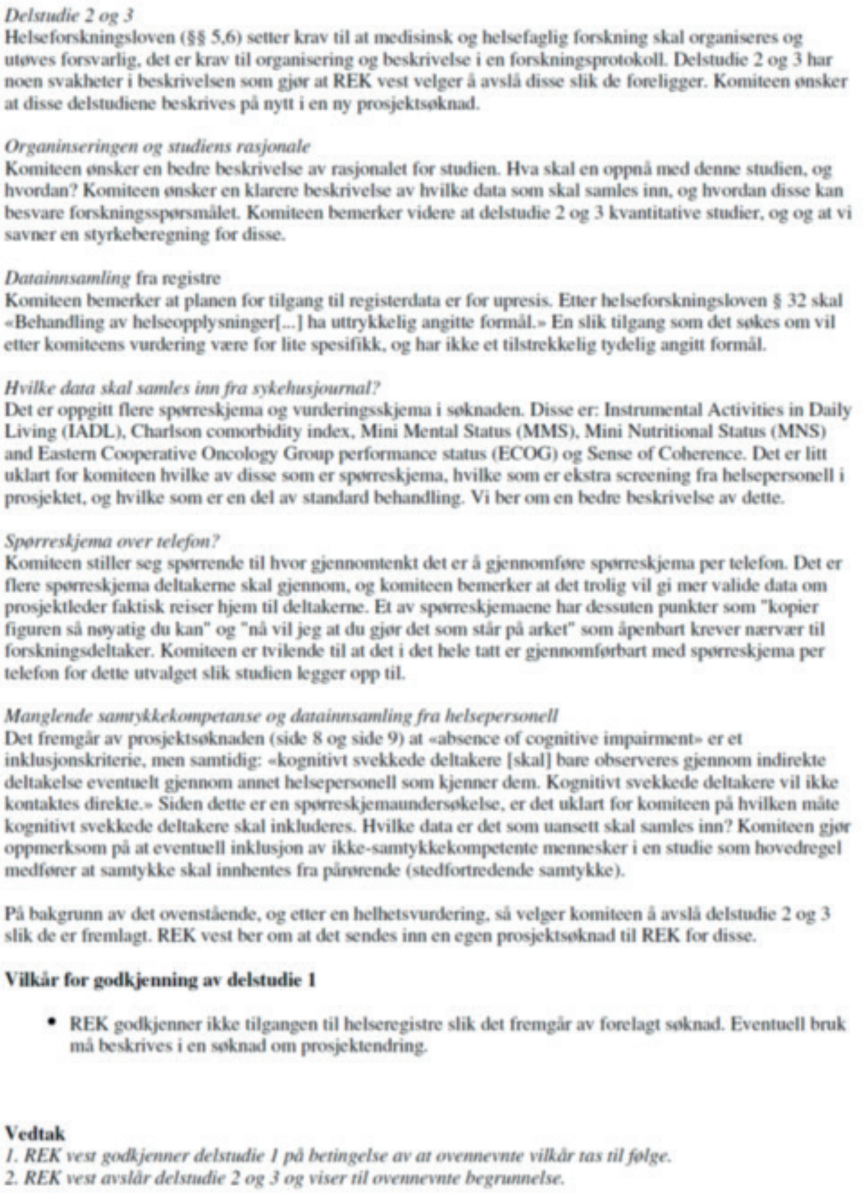
Det kan evt. søkes en prosjektendring når prosjektleder har et klarere bilde av akkurat hvilke data prosjektleder ønsker tilgang til. Det er ingenting i veien for at informasjonsskrivet om mulig bruk av registerdata blir stående slik som det gjør.

Besøksadresse:
Armauer Hansens Hus (AHH),
Tverrfløy Nord, 2 etasje. Rom
281. Haukelandsveien 28

Telefon: 55975000
E-post: rek-vest@uib.no
Web: http://helseforskning.etikkom.no/

All post og e-post som inngår i saksbehandlingen, bes adressert til REK vest og ikke til enkelte personer

Kindly address all mail and e-mails to the Regional Ethics Committee, REK vest, not to individual staff



Delstudie 2 og 3
Helseforskningsloven (§§ 5,6) setter krav til at medisinsk og helsefaglig forskning skal organiseres og utøves forsvarlig, det er krav til organisering og beskrivelse i en forskningsprotokoll. Delstudie 2 og 3 har noen svakheter i beskrivelsen som gjør at REK vest velger å avslå disse slik de foreligger. Komiteen ønsker at disse delstudiene beskrives på nytt i en ny prosjektsøknad.

Organinseringen og studiens rasjonale
Komiteen ønsker en bedre beskrivelse av rasjonalet for studien. Hva skal en oppnå med denne studien, og hvordan? Komiteen ønsker en klarere beskrivelse av hvilke data som skal samles inn, og hvordan disse kan besvare forskningsspørsmålet. Komiteen bemerker videre at delstudie 2 og 3 kvantitative studier, og og at vi savner en styrkeberegning for disse.

Datainnsamling fra registre
Komiteen bemerker at planen for tilgang til registerdata er for upresis. Etter helseforskningsloven § 32 skal «Behandling av helseopplysninger[...] ha uttrykkelig angitte formål.» En slik tilgang som det søkes om vil etter komiteens vurdering være for lite spesifikk, og har ikke et tilstrekkelig tydelig angitt formål.

Hvilke data skal samles inn fra sykehusjournal?
Det er oppgitt flere spørreskjema og vurderingsskjema i søknaden. Disse er: Instrumental Activities in Daily Living (IADL), Charlson comorbidity index, Mini Mental Status (MMS), Mini Nutritional Status (MNS) and Eastern Cooperative Oncology Group performance status (ECOG) og Sense of Coherence. Det er litt uklart for komiteen hvilke av disse som er spørreskjema, hvilke som er ekstra screening fra helsepersonell i prosjektet, og hvilke som er en del av standard behandling. Vi ber om en bedre beskrivelse av dette.

Spørreskjema over telefon?
Komiteen stiller seg spørrende til hvor gjennomtenkt det er å gjennomføre spørreskjema per telefon. Det er flere spørreskjema deltakerne skal gjennom, og komiteen bemerker at det trolig vil gi mer valide data om prosjektleder faktisk reiser hjem til deltakerne. Et av spørreskjemaene har dessuten punkter som "kopier figuren så nøyatig du kan" og "nå vil jeg at du gjør det som står på arket" som åpenbart krever nærvær til forskningsdeltaker. Komiteen er tvilende til at det i det hele tatt er gjennomførbart med spørreskjema per telefon for dette utvalget slik studien legger opp til.

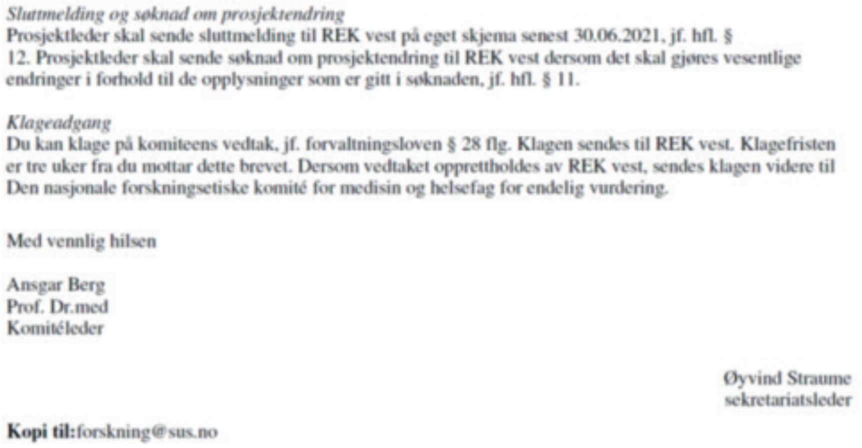
Manglende samtykkekompetanse og datainnsamling fra helsepersonell
Det fremgår av prosjektsøknaden (side 8 og side 9) at «absence of cognitive impairment» er et inklusjonskriterie, men samtidig: «kognitivt svekkede deltakere [skal] bare observeres gjennom indirekte deltakelse eventuelt gjennom annet helsepersonell som kjenner dem. Kognitivt svekkede deltakere vil ikke kontaktes direkte.» Siden dette er en spørreskjemaundersøkelse, er det uklart for komiteen på hvilken måte kognitivt svekkede deltakere skal inkluderes. Hvilke data er det som uansett skal samles inn? Komiteen gjør oppmerksom på at eventuell inklusjon av ikke-samtykkekompetente mennesker i en studie som hovedregel medfører at samtykke skal innhentes fra pårørende (stedfortredende samtykke).

På bakgrunn av det ovenstående, og etter en helhetsvurdering, så velger komiteen å avslå delstudie 2 og 3 slik de er fremlagt. REK vest ber om at det sendes inn en egen prosjektsøknad til REK for disse.

Vilkår for godkjenning av delstudie 1

- REK godkjenner ikke tilgangen til helseregistre slik det fremgår av forelagt søknad. Eventuell bruk må beskrives i en søknad om prosjektendring.

Vedtak
1. REK vest godkjenner delstudie 1 på betingelse av at ovennevnte vilkår tas til følge.
2. REK vest avslår delstudie 2 og 3 og viser til ovennevnte begrunnelse.



Sluttmelding og søknad om prosjektendring
Prosjektleder skal sende sluttmelding til REK vest på eget skjema senest 30.06.2021, jf. hfl. § 12. Prosjektleder skal sende søknad om prosjektendring til REK vest dersom det skal gjøres vesentlige endringer i forhold til de opplysninger som er gitt i søknaden, jf. hfl. § 11.

Klageadgang
Du kan klage på komiteens vedtak, jf. forvaltningsloven § 28 flg. Klagen sendes til REK vest. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK vest, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Med vennlig hilsen

Ansgar Berg
Prof. Dr.med
Komitéleder

Øyvind Straume
sekretariatsleder

Kopi til:forskning@sus.no

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	**Saksbehandler:**	**Telefon:**	**Vår dato:**	**Vår referanse:**
REK vest	Camilla Gjerstad	55978499	23.03.2018	2017/1739/REK vest
			Deres dato:	**Deres referanse:**
			22.01.2018	

Vår referanse må oppgis ved alle henvendelser

Kristina Eriksen
Helse Stavanger

2017/1739 Hvilke konsekvenser kirurgi for kolorektal kreft har på dagliglivet, mestringsevne og mortalitet for pasienter 80 år og eldre

Forskningsansvarlig: Helse Stavanger HF - Stavanger universitetssjukehus
Prosjektleder: Kristina Eriksen

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK vest) i møtet 07.03.2018. Vurderingen er gjort med hjemmel i helseforskningsloven (hfl.) § 10.

Prosjektomtale
Formålet er å undersøke faktorer som påvirker rekonvalesens, mestrings evne og økt overlevelse hos personer 80 år eller eldre behandlet kirurgisk for kreft i tykk- og endetarm. Studien har et kvantitativt eksplorerende design med forskningsspørsmålene 1) Er det noen forandringer i dagliglivet som muligens post-operative endringer (og/ eller)behov for hjelp fra helsetjenesten og sosial støtte tre måneder etter kurerende operasjon for kolorektalkreft blant pasienter 80 år og eldre, og er det noen assosiasjoner med opplevelse av sammenheng? Og 2) Hvilke faktorer eller komplikasjoner kan påvirker overlevelsen til pasienter som er 80 år og elder under det første året etter kurativ operasjon for kolorektalkreft, og er det noen assosiasjon mellom overlevelse og opplevelse av sammenheng? Datainnsamling vil være før operasjon, 3, 6, 9 og 12 måneder etter operasjonen. Datainnsamlingsmetodene vil være spørreskjema eller strukturert intervju samt data fra pasientjournal og nasjonale register.

Vurdering
Komiteen ba om tilbakemelding følgende:

- Forbedret protokoll med oppdatert fremdriftsplan og begrunnelse for bruk av hvert skjema.
- Informasjonsskrivet må revideres.
- Informasjon om prosjektleder må oppdateres.
- REK vest ba om refleksjon rundt antall koblinger til registre i protokollen.

Tilbakemelding fra prosjektleder
I tilbakemeldingen til komiteen er det redegjort for endringer som er gjort:

- Revidert informasjonsskriv er vedlagt.
- Revidert protokoll er vedlagt, der tidsplanen i protokollen er rettet opp.
- Kirsten Lode, hovedveileder for stipendiaten er nå prosjektleder.
- Kobling til registre: Studie 1 og studie 2 har datainnsamling på ulike tidspunkt og søker peker på at det er nødvendig med to oppslag i registrene.

Besøksadresse:
Armauer Hansens Hus (AHH),
Tverrfløy Nord, 2 etasje. Rom
281. Haukelandsveien 28

Telefon: 55975000
E-post: post@helseforskning.etikkom.no
Web: http://helseforskning.etikkom.no/

All post og e-post som inngår i saksbehandlingen, bes adressert til REK vest og ikke til enkelte personer

Kindly address all mail and e-mails to the Regional Ethics Committee, REK vest, not to individual staff

- Spørreskjemaene og screeningverktøyene: Formålet med hvert skjema og verktøy er beskrevet.

Vurdering av tilbakemeldingen
Prosjektleder har gitt en tilbakemeldingen som besvarer komiteens merknader på en tilfredsstillende måte. I informasjonsskrivet må dato for prosjektslutt samsvare med angitt dato som det er søkt om i søknadsskjemaet, dvs. 31.12.2021. Komiteen har ellers ingen ytterligere merknader til studien.

Vilkår
Informasjonsskrivet må revideres.

Vedtak
REK vest godkjenner prosjektet på betingelse av at ovennevnte vilkår tas til følge.

Sluttmelding og søknad om prosjektendring
Prosjektleder skal sende sluttmelding til REK vest på eget skjema senest 30.06.2022, jf. hfl. § 12. Prosjektleder skal sende søknad om prosjektendring til REK vest dersom det skal gjøres vesentlige endringer i forhold til de opplysninger som er gitt i søknaden, jf. hfl. § 11.

Klageadgang
Du kan klage på komiteens vedtak, jf. forvaltningsloven § 28 flg. Klagen sendes til REK vest. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK vest, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Med vennlig hilsen

Marit Grønning
dr.med. professor
komitéleder

Camilla Gjerstad
rådgiver

Kopi til:forskning@sus.no

Alle skriftlige henvendelser om saken må sendes via REK-portalen
Du finner informasjon om REK på våre hjemmesider rekportalen.no

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	**Saksbehandler:**	**Telefon:**	**Vår dato:**	**Vår referanse:**
REK vest	Jessica Svärd	55978497	24.04.2020	19983
			Deres referanse:	

Kirsten Lode

19983 Hvilke konsekvenser kirurgi for kolorektal kreft har på dagliglivet, mestringsevne og mortalitet for pasienter 80 år og eldre

Forskningsansvarlig: Helse Stavanger HF - Stavanger universitetssjukehus

Søker: Kirsten Lode

REKs vurdering

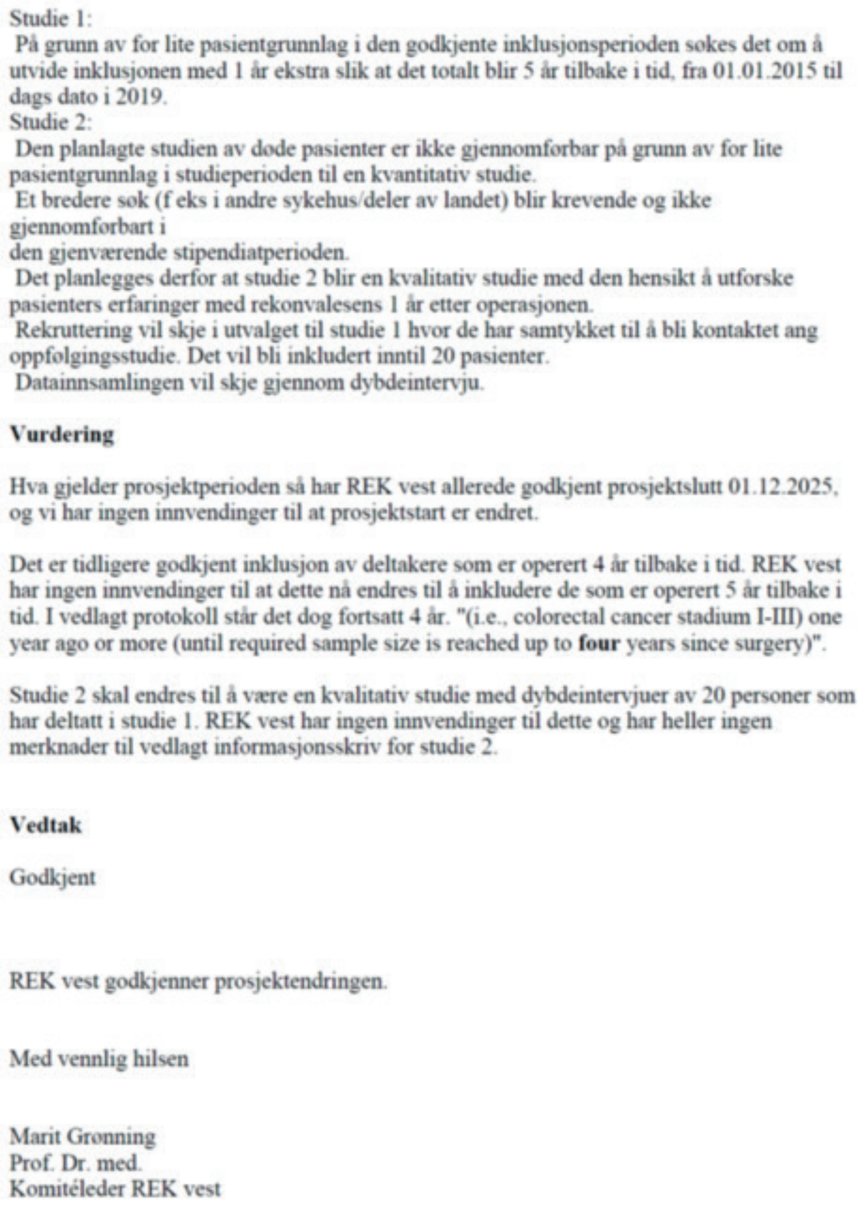
Vi viser til søknad om prosjektendring mottatt 12.03.2020 for ovennevnte forskningsprosjekt. Søknaden er behandlet av leder for REK vest på delegert fullmakt fra komiteen, med hjemmel i forskningsetikkforskriften § 7, første ledd, tredje punktum. Søknaden er vurdert med hjemmel i helseforskningsloven § 11.

Omsøkte endringer:

- Ny versjon av forskningsprotokoll
- Ny/endret forespørsel om deltakelse og samtykkeerklæring
- Endring i prosjektperiode: Ny estimert startdato: 12.03.2020 og ny estimert sluttdato: 01.12.2025.

Begrunnelse for endring:

Endringer ved forskningsprotokollen 2020
Design:
Studien har skiftet fra rent kvantitativt til mixed method design.



Studie 1:
På grunn av for lite pasientgrunnlag i den godkjente inklusjonsperioden søkes det om å utvide inklusjonen med 1 år ekstra slik at det totalt blir 5 år tilbake i tid, fra 01.01.2015 til dags dato i 2019.
Studie 2:
Den planlagte studien av døde pasienter er ikke gjennomførbar på grunn av for lite pasientgrunnlag i studieperioden til en kvantitativ studie.
Et bredere søk (f eks i andre sykehus/deler av landet) blir krevende og ikke gjennomførbart i den gjenværende stipendiatperioden.
Det planlegges derfor at studie 2 blir en kvalitativ studie med den hensikt å utforske pasienters erfaringer med rekonvalesens 1 år etter operasjonen.
Rekruttering vil skje i utvalget til studie 1 hvor de har samtykket til å bli kontaktet ang oppfølgingsstudie. Det vil bli inkludert inntil 20 pasienter.
Datainnsamlingen vil skje gjennom dybdeintervju.

Vurdering

Hva gjelder prosjektperioden så har REK vest allerede godkjent prosjektslutt 01.12.2025, og vi har ingen innvendinger til at prosjektstart er endret.

Det er tidligere godkjent inklusjon av deltakere som er operert 4 år tilbake i tid. REK vest har ingen innvendinger til at dette nå endres til å inkludere de som er operert 5 år tilbake i tid. I vedlagt protokoll står det dog fortsatt 4 år. "(i.e., colorectal cancer stadium I-III) one year ago or more (until required sample size is reached up to **four** years since surgery)".

Studie 2 skal endres til å være en kvalitativ studie med dybdeintervjuer av 20 personer som har deltatt i studie 1. REK vest har ingen innvendinger til dette og har heller ingen merknader til vedlagt informasjonsskriv for studie 2.

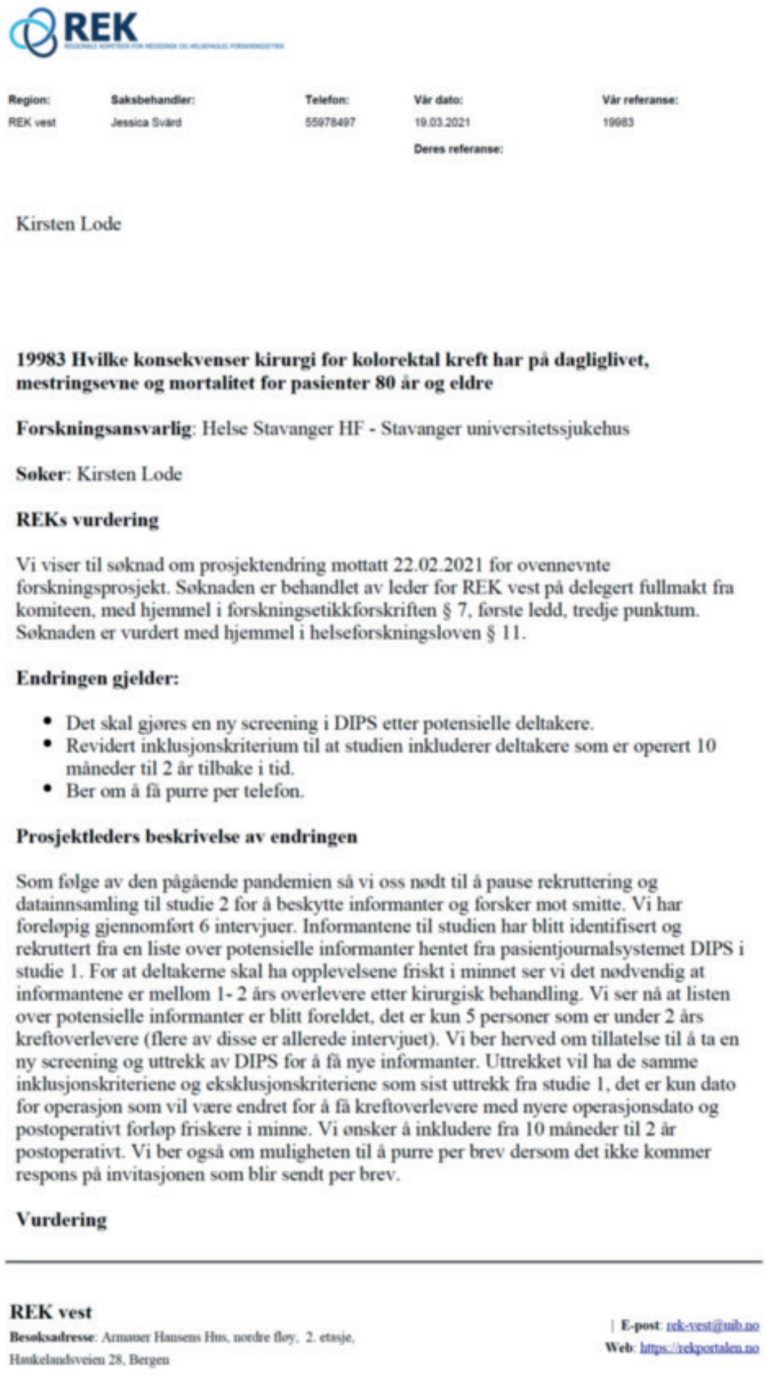
Vedtak

Godkjent

REK vest godkjenner prosjektendringen.

Med vennlig hilsen

Marit Grønning
Prof. Dr. med.
Komitéleder REK vest



REK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK vest	Jessica Svärd	55978497	19.03.2021	19983
			Deres referanse:	

Kirsten Lode

19983 Hvilke konsekvenser kirurgi for kolorektal kreft har på dagliglivet, mestringsevne og mortalitet for pasienter 80 år og eldre

Forskningsansvarlig: Helse Stavanger HF - Stavanger universitetssjukehus

Søker: Kirsten Lode

REKs vurdering

Vi viser til søknad om prosjektendring mottatt 22.02.2021 for ovennevnte forskningsprosjekt. Søknaden er behandlet av leder for REK vest på delegert fullmakt fra komiteen, med hjemmel i forskningsetikkforskriften § 7, første ledd, tredje punktum. Søknaden er vurdert med hjemmel i helseforskningsloven § 11.

Endringen gjelder:

- Det skal gjøres en ny screening i DIPS etter potensielle deltakere.
- Revidert inklusjonskriterium til at studien inkluderer deltakere som er operert 10 måneder til 2 år tilbake i tid.
- Ber om å få purre per telefon.

Prosjektleders beskrivelse av endringen

Som følge av den pågående pandemien så vi oss nødt til å pause rekruttering og datainnsamling til studie 2 for å beskytte informanter og forsker mot smitte. Vi har foreløpig gjennomført 6 intervjuer. Informantene til studien har blitt identifisert og rekruttert fra en liste over potensielle informanter hentet fra pasientjournalsystemet DIPS i studie 1. For at deltakerne skal ha opplevelsene friskt i minnet ser vi det nødvendig at informantene er mellom 1- 2 års overlevere etter kirurgisk behandling. Vi ser nå at listen over potensielle informanter er blitt foreldet, det er kun 5 personer som er under 2 års kreftoverlevere (flere av disse er allerede intervjuet). Vi ber herved om tillatelse til å ta en ny screening og uttrekk av DIPS for å få nye informanter. Uttrekket vil ha de samme inklusjonskriteriene og eksklusjonskriteriene som sist uttrekk fra studie 1, det er kun dato for operasjon som vil være endret for å få kreftoverlevere med nyere operasjonsdato og postoperativt forløp friskere i minne. Vi ønsker å inkludere fra 10 måneder til 2 år postoperativt. Vi ber også om muligheten til å purre per brev dersom det ikke kommer respons på invitasjonen som blir sendt per brev.

Vurdering

REK vest godkjenner at det gjøres et nytt uttrekk fra DIPS for å identifisere nye deltakere, og at inklusjonskrierieriene endres til å inkludere deltakere 10 måneder til 2 år etter operasjon.

REK vest godkjenner ikke at det purres på telefon når forespørsel om deltakelse ikke er besvart siden dette anses for påtrengende. Det bør heller vurderes om det er mulig å kalle inn personer over 80 år som er operert for kolorektal kreft til etterkontroll.

Vilkår

Det kan ikke purres på deltakelse per telefon.

Vedtak

Godkjent med vilkår

REK vest godkjenner prosjektendringen på betingelse at nevnte vilkår tas til følge.

Vennlig hilsen,

Marit Grønning
Prof. Dr. med.
Komitéleder

Jessica Svärd
rådgiver

Klageadgang
Du kan klage på komiteens vedtak, jf. forvaltningsloven § 28 flg. Klagen sendes til REK vest. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK vest, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag (NEM) for endelig vurdering.

Appendix 5 - Information letter study 1

Eldre med kreft i tykk- og endetarm – 17.12.2015

Forespørsel om deltakelse i forskningsprosjekt

«Livet etter kirurgisk behandling for kreft i tykk- og endetarm hos personer i en alder av 80 og over: Del 1»

Bakgrunn og hensikt

Dette er et spørsmål til deg om å delta i et forskningsprosjekt for å bedre behandlingstilbudet til pasienter som skrives ut etter operasjon for kreft i tykk- og endetarm. Vi spør deg om å delta i studien fordi det planlegges å gjennomføre en slik operasjon ved Stavanger Universitetssjukehus og du er i alderen 80 år eller eldre.

Det overordnede målet med denne studien er å få mer kunnskap om hva det er som påvirker rehabilitering etter en operasjon i tykk- og endetarm og kartlegge hva som skjer det første året etter operasjonen. Det er Stavanger Universitetssjukehus som er ansvarlig for denne studien.

Hva innebærer studien?

I undersøkelsen vil vi kartlegge din helsetilstand fire uker etter operasjonen. Tidspunkt og plass for dette intervjuet vil avtales på forhånd for å passe din timeplan. Det er ønskelig med innsyn i journalen din dersom det er nødvendig for å hente informasjon fra innleggelsen og eventuelle reinnleggelser.

Mulige fordeler og ulemper

Etter operasjonen er det ikke en standard behandling fastsatt, behovet vurderes individuelt. Dersom du ikke ønsker å delta i studien vil ikke dette ha noen påvirkning på den behandling og oppfølging du vil få i etterkant av innleggelse ved Stavanger Universitetssjukehus.

Hva skjer med informasjonen om deg?

Informasjonen som registreres om deg skal kun brukes som beskrevet i hensikten med studien. Alle opplysninger vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste. Det betyr at opplysningene er avidentifisert. Det er kun autorisert personell knyttet til prosjektet som har adgang til navnelisten og som kan finne tilbake til deg. Ved innsyn i journal er det kun opplysninger knyttet til dine diagnoser og behandling etter innleggelse for operasjon for tykk- og endetarmskreft som vil bli brukt. Den informasjonen som samles vil bli slettet når prosjektet er slutt, forespeilet i løpet av 2020.

Frivillig deltakelse

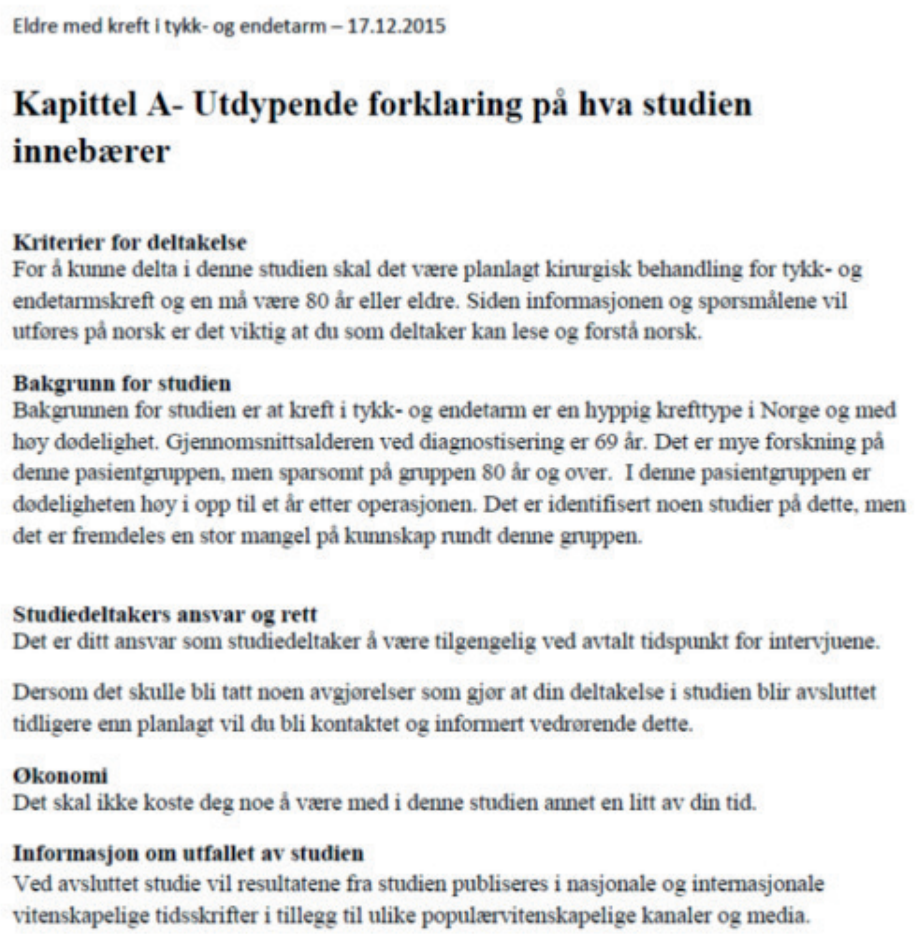
Det er frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien, da vil informasjonen din bli slettet dersom den ikke allerede inngår i analysearbeid eller er brukt i vitenskapelige publikasjoner. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Dersom du senere ønsker å trekke deg eller

Eldre med kreft i tykk- og endetarm – 17.12.2015

har spørsmål om studien kan du kontakte Kristina Sundt Eriksen eller Kirsten Lode ved forskningsavdelingen, Stavanger Universitetssjukehus.

Med vennlig hilsen

Kristina S. Eriksen	Kirsten Lode
Sykepleier	Sykepleier
Stipendiat	Forskningssjef
Tlf 98639667	Tlf 51513778



Eldre med kreft i tykk- og endetarm – 17.12.2015

Kapittel A- Utdypende forklaring på hva studien innebærer

Kriterier for deltakelse
For å kunne delta i denne studien skal det være planlagt kirurgisk behandling for tykk- og endetarmskreft og en må være 80 år eller eldre. Siden informasjonen og spørsmålene vil utføres på norsk er det viktig at du som deltaker kan lese og forstå norsk.

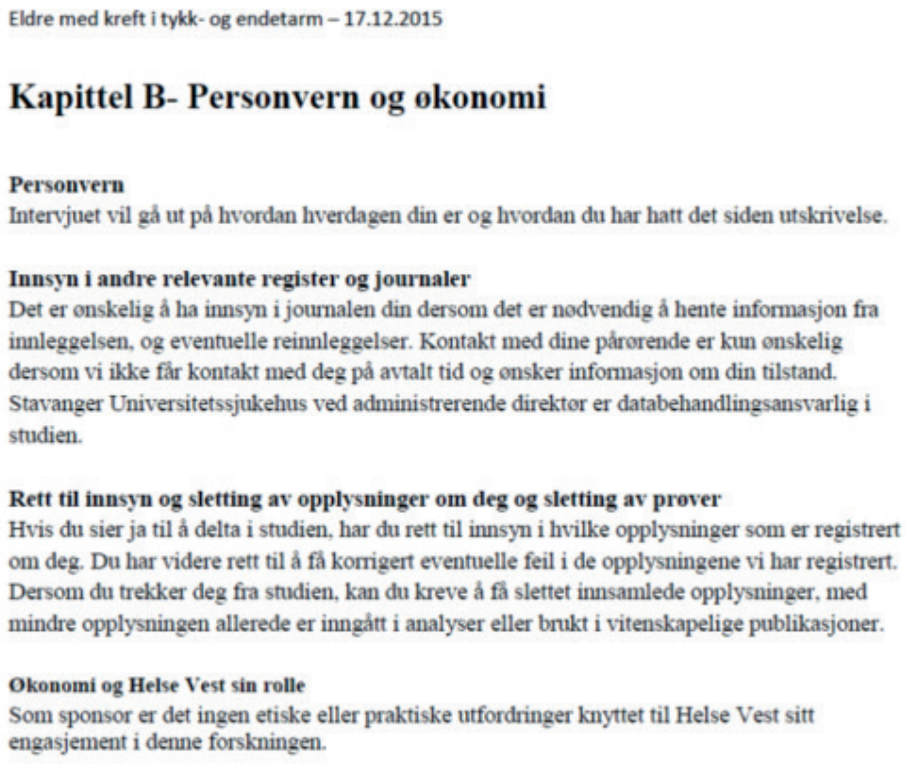
Bakgrunn for studien
Bakgrunnen for studien er at kreft i tykk- og endetarm er en hyppig krefttype i Norge og med høy dødelighet. Gjennomsnittsalderen ved diagnostisering er 69 år. Det er mye forskning på denne pasientgruppen, men sparsomt på gruppen 80 år og over. I denne pasientgruppen er dødeligheten høy i opp til et år etter operasjonen. Det er identifisert noen studier på dette, men det er fremdeles en stor mangel på kunnskap rundt denne gruppen.

Studiedeltakers ansvar og rett
Det er ditt ansvar som studiedeltaker å være tilgengelig ved avtalt tidspunkt for intervjuene.

Dersom det skulle bli tatt noen avgjørelser som gjør at din deltakelse i studien blir avsluttet tidligere enn planlagt vil du bli kontaktet og informert vedrørende dette.

Økonomi
Det skal ikke koste deg noe å være med i denne studien annet en litt av din tid.

Informasjon om utfallet av studien
Ved avsluttet studie vil resultatene fra studien publiseres i nasjonale og internasjonale vitenskapelige tidsskrifter i tillegg til ulike populærvitenskapelige kanaler og media.



Eldre med kreft i tykk- og endetarm – 17.12.2015

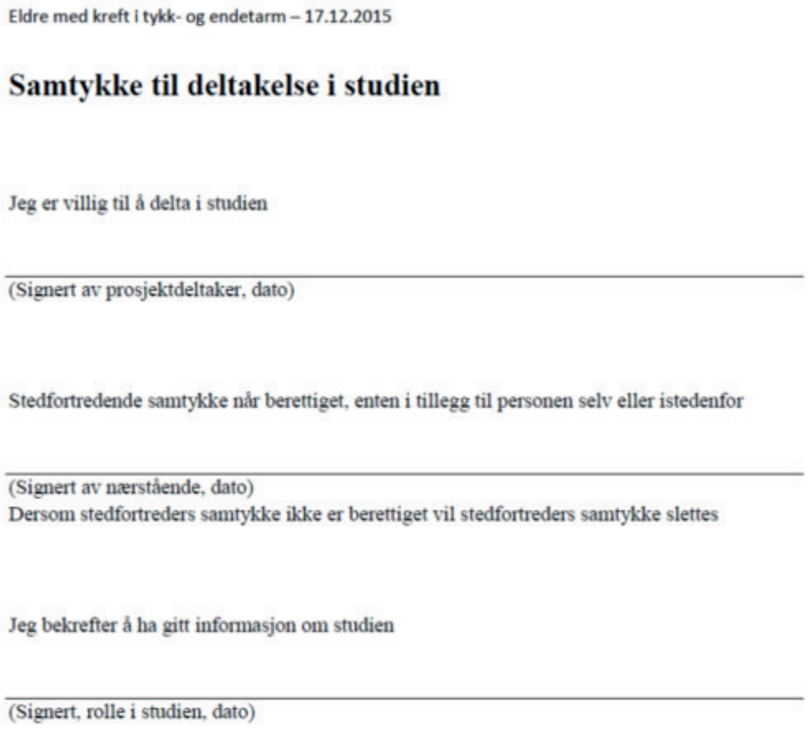
Kapittel B- Personvern og økonomi

Personvern
Intervjuet vil gå ut på hvordan hverdagen din er og hvordan du har hatt det siden utskrivelse.

Innsyn i andre relevante register og journaler
Det er ønskelig å ha innsyn i journalen din dersom det er nødvendig å hente informasjon fra innleggelsen, og eventuelle reinnleggelser. Kontakt med dine pårørende er kun ønskelig dersom vi ikke får kontakt med deg på avtalt tid og ønsker informasjon om din tilstand. Stavanger Universitetssjukehus ved administrerende direktør er databehandlingsansvarlig i studien.

Rett til innsyn og sletting av opplysninger om deg og sletting av prøver
Hvis du sier ja til å delta i studien, har du rett til innsyn i hvilke opplysninger som er registrert om deg. Du har videre rett til å få korrigert eventuelle feil i de opplysningene vi har registrert. Dersom du trekker deg fra studien, kan du kreve å få slettet innsamlede opplysninger, med mindre opplysningen allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Økonomi og Helse Vest sin rolle
Som sponsor er det ingen etiske eller praktiske utfordringer knyttet til Helse Vest sitt engasjement i denne forskningen.



Eldre med kreft i tykk- og endetarm – 17.12.2015

Samtykke til deltakelse i studien

Jeg er villig til å delta i studien

(Signert av prosjektdeltaker, dato)

Stedfortredende samtykke når berettiget, enten i tillegg til personen selv eller istedenfor

(Signert av nærstående, dato)
Dersom stedfortreders samtykke ikke er berettiget vil stedfortreders samtykke slettes

Jeg bekrefter å ha gitt informasjon om studien

(Signert, rolle i studien, dato)

Appendix 6 - Information letter study 2

FORESPØRSEL OM DELTAKELSE I FORSKNINGSPROSJEKTET

HVILKE KONSEKVENSER KIRURGI FOR KOLOREKTAL KREFT HAR PÅ DAGLIGLIVET, MESTRINGSEVNE OG OVERLEVELSE FOR PASIENTER 80 ÅR OG ELDRE

Dette er et spørsmål til deg om å delta i et forskningsprosjekt for å bedre behandlingstilbudet til pasienter som skrives ut etter operasjon for kreft i tykk- og endetarm. Det overordnede målet med denne studien er å få mer kunnskap om hva det er som påvirker rehabiliteringen etter en operasjon i tykk- og endetarm og kartlegge hva som skjer det første året etter operasjonen.

Vi spør deg om å delta i studien fordi du har gjennomført en slik operasjon og du er 80 år eller eldre. Det er Stavanger Universitetssjukehus som er ansvarlig for denne studien.

HVA INNEBÆRER PROSJEKTET?

Prosjektet innebærer å svare på en spørreundersøkelse over telefon med forsker. Tidspunktet for telefonsamtalen avtales på forhånd for å passe inn i din timeplan. En papirutgave av spørreundersøkelsen er vedlagt dette informasjonsskrivet slik at du har et eksemplar av undersøkelsen tilgjengelig under telefonsamtalen. Spørreundersøkelsen vil ta ca 45 min.

I prosjektet vil vi innhente og registrere opplysninger om deg. Vi vil kartlegge din funksjon, mestringsevne, sosiale støtte og registrere om du opplever noen endringer i din helsetilstand etter operasjonen. Det er ønskelig med innsyn i journalen din for å hente informasjon fra innleggelsen, eventuelle reinnleggelser og om endringer i din helsetilstand. I tillegg kan det være aktuelt å hente ut informasjonen fra følgende offentlige register: Komplikasjonsregisteret (NoRGast), hvor eventuelle komplikasjoner etter operasjonen er registrert og Norsk pasientregister (NPR), som registrerer om du er blitt behandlet evt re-innlagt ved andre norske sykehus.

MULIGE FORDELER OG ULEMPER

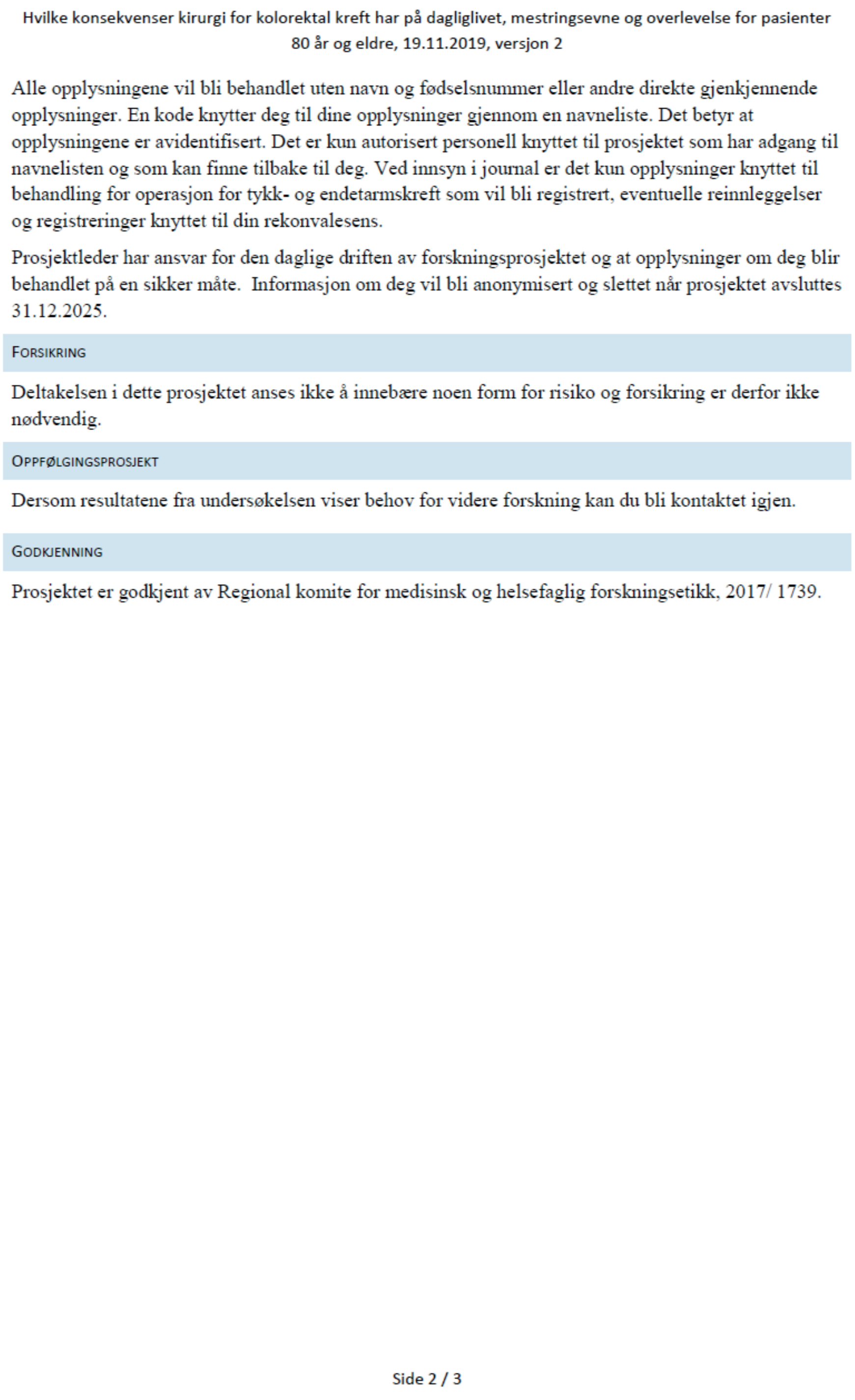
Dersom du ikke ønsker å delta i studien vil ikke dette ha noen påvirkning på den behandlingen og oppfølgingen du mottar.

FRIVILLIG DELTAKELSE OG MULIGHET FOR Å TREKKE SITT SAMTYKKE

Det er frivillig å delta i prosjektet. **Dersom du ønsker å delta, undertegner du samtykkeerklæringen på side tre og sender den tilbake i vedlagt frankert konvolutt**. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke. Dette vil ikke få konsekvenser for din videre behandling. Dersom du trekker deg fra prosjektet, kan du kreve å få slettet innsamlede opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner. Dersom du senere ønsker å trekke deg eller har spørsmål til prosjektet, kan du kontakte Kristina Sundt Eriksen på telefon 98639667 eller mail kristina.s.eriksen@gmail.com.

HVA SKJER MED INFORMASJONEN OM DEG?

Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Du har rett til innsyn i hvilke opplysninger som er registrert om deg og rett til å få korrigert eventuelle feil i de opplysningene som er registrert.



Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste. Det betyr at opplysningene er avidentifisert. Det er kun autorisert personell knyttet til prosjektet som har adgang til navnelisten og som kan finne tilbake til deg. Ved innsyn i journal er det kun opplysninger knyttet til behandling for operasjon for tykk- og endetarmskreft som vil bli registrert, eventuelle reinnleggelser og registreringer knyttet til din rekonvalesens.

Prosjektleder har ansvar for den daglige driften av forskningsprosjektet og at opplysninger om deg blir behandlet på en sikker måte. Informasjon om deg vil bli anonymisert og slettet når prosjektet avsluttes 31.12.2025.

FORSIKRING

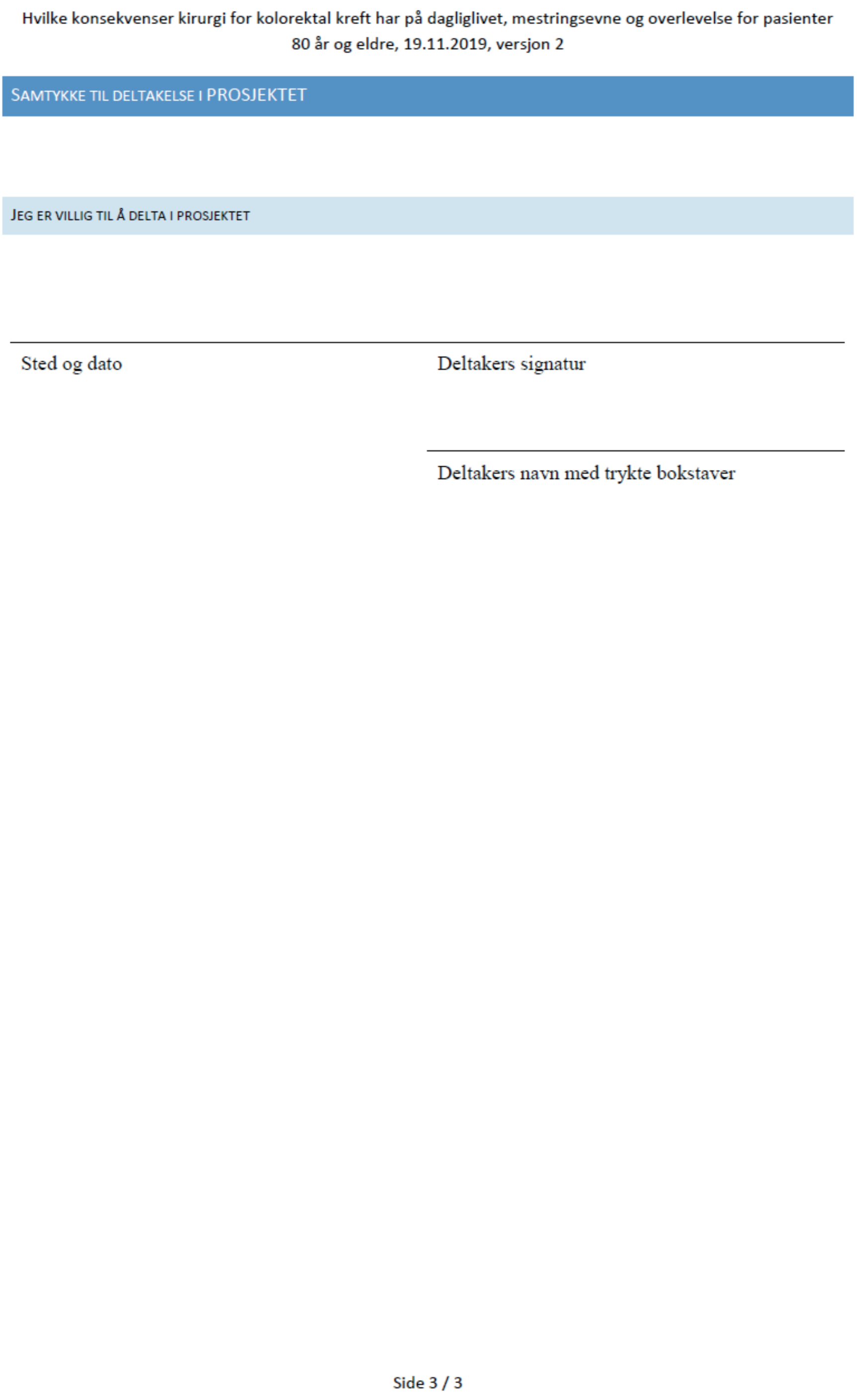
Deltakelsen i dette prosjektet anses ikke å innebære noen form for risiko og forsikring er derfor ikke nødvendig.

OPPFØLGINGSPROSJEKT

Dersom resultatene fra undersøkelsen viser behov for videre forskning kan du bli kontaktet igjen.

GODKJENNING

Prosjektet er godkjent av Regional komite for medisinsk og helsefaglig forskningsetikk, 2017/ 1739.



Hvilke konsekvenser kirurgi for kolorektal kreft har på dagliglivet, mestringsevne og overlevelse for pasienter 80 år og eldre, 19.11.2019, versjon 2

SAMTYKKE TIL DELTAKELSE I PROSJEKTET

JEG ER VILLIG TIL Å DELTA I PROSJEKTET

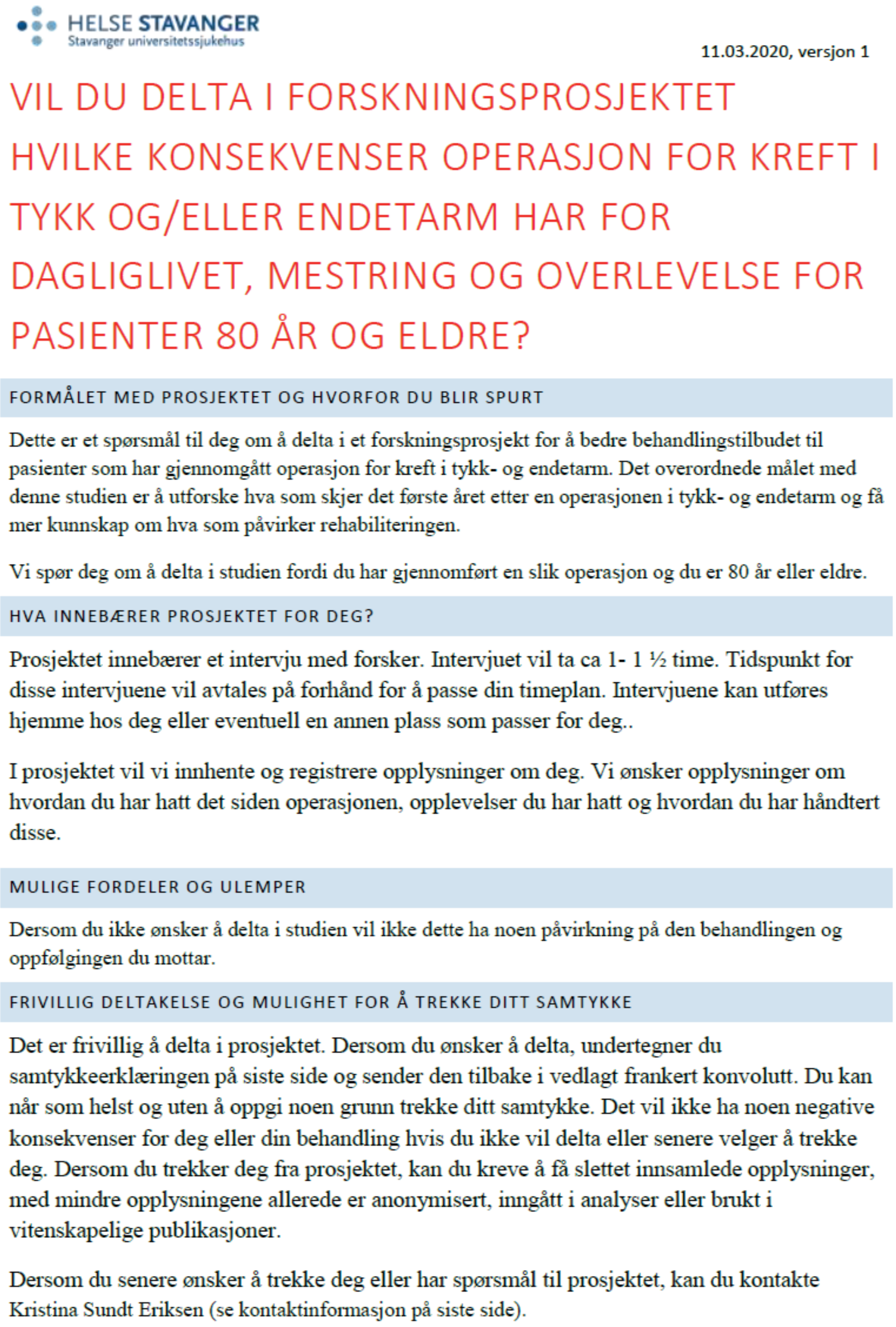
Sted og dato

Deltakers signatur

Deltakers navn med trykte bokstaver

Side 3 / 3

Appendix 7 - Information letter study 3



HELSE STAVANGER
Stavanger universitetssjukehus

11.03.2020, versjon 1

VIL DU DELTA I FORSKNINGSPROSJEKTET HVILKE KONSEKVENSER OPERASJON FOR KREFT I TYKK OG/ELLER ENDETARM HAR FOR DAGLIGLIVET, MESTRING OG OVERLEVELSE FOR PASIENTER 80 ÅR OG ELDRE?

FORMÅLET MED PROSJEKTET OG HVORFOR DU BLIR SPURT

Dette er et spørsmål til deg om å delta i et forskningsprosjekt for å bedre behandlingstilbudet til pasienter som har gjennomgått operasjon for kreft i tykk- og endetarm. Det overordnede målet med denne studien er å utforske hva som skjer det første året etter en operasjonen i tykk- og endetarm og få mer kunnskap om hva som påvirker rehabiliteringen.

Vi spør deg om å delta i studien fordi du har gjennomført en slik operasjon og du er 80 år eller eldre.

HVA INNEBÆRER PROSJEKTET FOR DEG?

Prosjektet innebærer et intervju med forsker. Intervjuet vil ta ca 1- 1 ½ time. Tidspunkt for disse intervjuene vil avtales på forhånd for å passe din timeplan. Intervjuene kan utføres hjemme hos deg eller eventuell en annen plass som passer for deg..

I prosjektet vil vi innhente og registrere opplysninger om deg. Vi ønsker opplysninger om hvordan du har hatt det siden operasjonen, opplevelser du har hatt og hvordan du har håndtert disse.

MULIGE FORDELER OG ULEMPER

Dersom du ikke ønsker å delta i studien vil ikke dette ha noen påvirkning på den behandlingen og oppfølgingen du mottar.

FRIVILLIG DELTAKELSE OG MULIGHET FOR Å TREKKE DITT SAMTYKKE

Det er frivillig å delta i prosjektet. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side og sender den tilbake i vedlagt frankert konvolutt. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke. Det vil ikke ha noen negative konsekvenser for deg eller din behandling hvis du ikke vil delta eller senere velger å trekke deg. Dersom du trekker deg fra prosjektet, kan du kreve å få slettet innsamlede opplysninger, med mindre opplysningene allerede er anonymisert, inngått i analyser eller brukt i vitenskapelige publikasjoner.

Dersom du senere ønsker å trekke deg eller har spørsmål til prosjektet, kan du kontakte Kristina Sundt Eriksen (se kontaktinformasjon på siste side).

HELSE STAVANGER
Stavanger universitetssjukehus

11.03.2020, versjon 1

HVA SKJER MED OPPLYSNINGENE OM DEG?

Opplysningene som registreres om deg skal kun brukes slik som beskrevet under formålet med prosjektet, og planlegges brukt til 2025. Eventuelle utvidelser i bruk og oppbevaringstid kan kun skje etter godkjenning fra REK og andre relevante myndigheter. Du har rett til innsyn i hvilke opplysninger som er registrert om deg og rett til å få korrigert eventuelle feil i de opplysningene som er registrert. Du har også rett til å få innsyn i sikkerhetstiltakene ved behandling av opplysningene.

Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste. Det er kun stipendiat og veiledere som har tilgang til denne listen.

Opplysningene om deg vil bli oppbevart i fem år etter prosjektslutt av kontrollhensyn.

FORSIKRING

Deltakelsen i dette prosjektet anses ikke å innebære noen form for risiko og forsikring er derfor ikke nødvendig.

OPPFØLGINGSPROSJEKT

Dersom resultatene fra undersøkelsen viser behov for videre forskning kan du bli kontaktet igjen.

GODKJENNINGER

Regional komité for medisinsk og helsefaglig forskningsetikk har gjort en forskningsetisk vurdering og godkjent prosjektet, saksnr. 2017/ 1739.

Det er Stavanger Universitetssjukehus som er ansvarlig for denne studien.

KONTAKTOPPLYSNINGER

Dersom du har spørsmål til prosjektet eller ønsker å trekke deg fra deltakelse, kan du kontakte Kristina Sundt Eriksen på telefon 98639667 eller mail kristina.s.eriksen@sus.no. Dersom du har spørsmål om personvernet i prosjektet, kan du kontakte personvernombudet ved institusjonen: personvernombudet@sus.no

HELSE STAVANGER
Stavanger universitetssjukehus

11.03.2020, versjon 1

JEG SAMTYKKER TIL Å DELTA I PROSJEKTET OG TIL AT MINE PERSONOPPLYSNINGER BRUKES SLIK DET ER BESKREVET

Sted og dato

Deltakers signatur

Deltakers navn med trykte bokstaver