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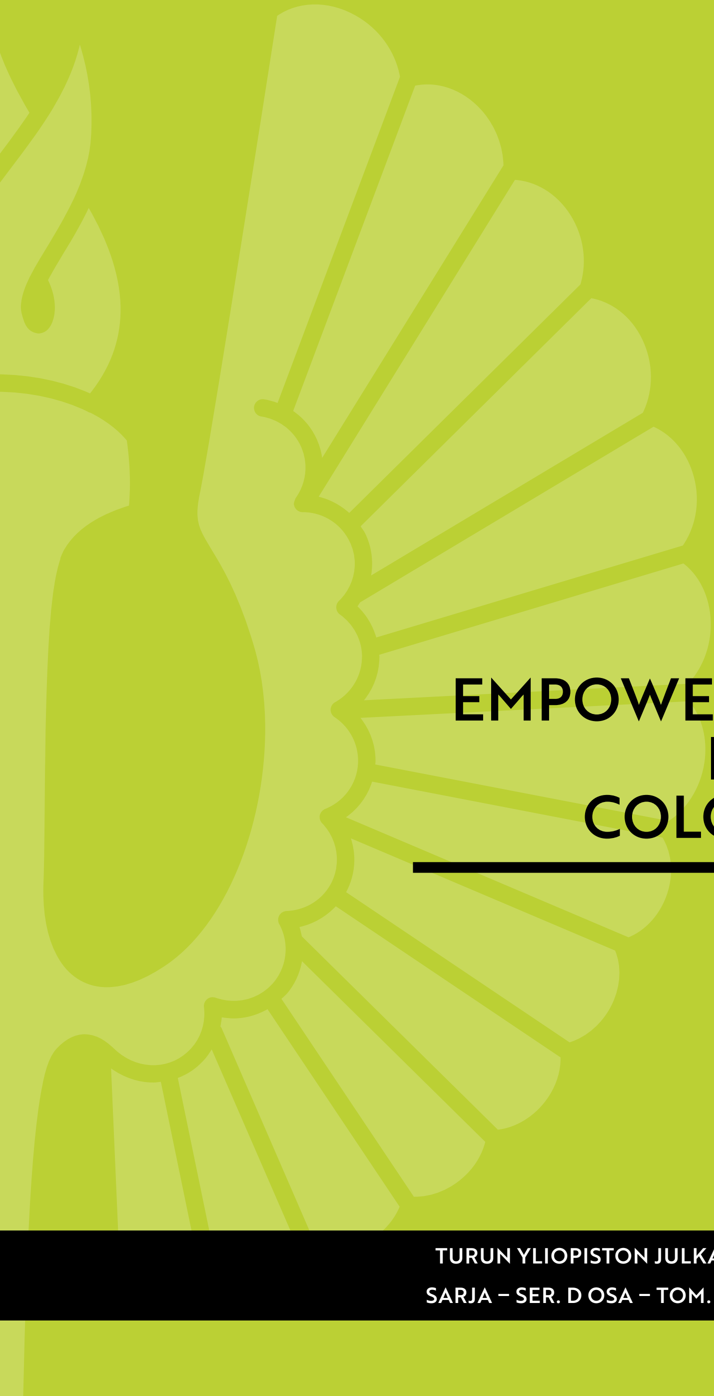

EMPOWERING EDUCATION IN PATIENTS WITH COLORECTAL CANCER

Leena Tuominen

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SARJA – SER. D OSA – TOM. 1733 | MEDICA – ODONTOLOGICA | TURKU 2023

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To my family

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LEENA TUOMINEN: Empowering education in patients with colorectal cancer
Doctoral Dissertation, 162 pp.
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ABSTRACT

Today, as cancer morbidity and consequently the pressure on healthcare systems have increased, the effectiveness of nursing interventions is emphasised in the care of patients with cancer. Research on empowering education for cancer patients is, however, limited.

The goal of this study was to produce new knowledge of the effect of empowering patient education in patients with colorectal cancer. In the first phase, an overview of systematic reviews (n=17) was conducted on nursing interventions and their effectiveness in patients with cancer. Interviews were conducted with patients with colorectal cancer (n=15) on their expectations for nursing during chemotherapy. Knowledge produced in the first phase was also used in the planning of the method and content of the intervention in this study. In the second phase, an empowering education intervention was developed, and its effect was tested in a randomised controlled trial for patient-reported outcomes and register data in patients with colorectal cancer (43 + 40).

According to the overview of systematic reviews, the nursing interventions were educational, psychosocial, psychological, activity-based as well as interventions supporting coping. Based on the results, an educational intervention, which also included elements supporting patients' coping was selected for this study. According to the patient interviews, patients' expectations consisted of (1) empowering knowledge, (2) human encounters, and (3) good care. In this study, these themes were used in offering empowering knowledge of nutrition impact side-effects and support for self-care using teach-back method. The difference in change was nearly significantly higher in the activation level and statistically significant in the knowledge level associated with malnutrition and in the number of additional contacts to the outpatient clinic in favour of the intervention group

As a conclusion, empowering patient education can improve the patient activation level and knowledge in patients with colorectal cancer. It can also reduce contacts to the outpatient clinic due to nutrition impact side effects, thus reduce health care costs.

KEYWORDS: effectiveness of nursing, empowering patient education, nutrition impact side effects, patient with colorectal cancer

TURUN YLIOPISTO
Lääketieteellinen tiedekunta
Hoitotiede
LEENA TUOMINEN: Suolistosyöpää sairastavien potilaiden voimavaroja tukeva ohjaus
Väitöskirja, 162 s.
Hoitotieteen tohtoriohjelma
Elokuu 2023

TIIVISTELMÄ

Sairastuvuus syöpään ja sen myötä paine terveydenhuoltojärjestelmää kohtaan lisääntyy, jolloin hoitotyön toimintojen vaikuttavuus hoitotyössä korostuu. Tutkimus syöpää sairastavien potilaiden voimavaraistumista tukevasta ohjauksesta on kuitenkin vähäistä.

Tutkimuksen tavoitteena oli tuottaa uutta tietoa potilaan voimavaroja tukevan ohjauksen vaikuttavuudesta. Ensimmäisessä vaiheessa analysoitiin kirjallisuuskatsauksen avulla (n=17) hoitotyön interventioita ja niiden vaikutusta syöpää sairastavien potilaiden hoidossa. Suolistosyöpää sairastavia potilaita (n=15) haastateltiin heidän odotuksistaan hoitotyötä kohtaan solunsalpaajahoidon aikana. Tuotettua tietoa hyödynnettiin myös tämän tutkimuksen intervention suunnittelussa. Toisessa vaiheessa kehitettiin potilaiden voimavaraistumista tukeva ohjausinterventio ja arvioitiin sen vaikutusta suolistosyöpää sairastaviin potilaisiin (43 + 40) satunnaistetun kontrolloidun tutkimusasetelman avulla.

Hoitotyön interventiot olivat opetuksellisia, psykososiaalisia, psykologisia, liikunnallisia ja potilaiden selviytymistä tukevia. Tässä tutkimuksessa interventioksi valikoitui opetuksellinen interventio, joka sisälsi myös selviytymistä tukevia elementtejä. Potilaiden odotukset koostuivat 1) voimavaraistumista tukevasta tiedosta 2) inhimillisestä kohtaamisesta ja 3) hyvästä hoidosta. Näitä teemoja hyödynnettiin tarjoamalla potilaille voimavaraistumista tukevaa tietoa ravinnon saantia heikentävistä sivuvaikutuksista ja niiden itsehoidosta takaisin opettamisen mallin avulla. Aktivaatiotaso kasvoi koeryhmässä melkein merkitsevästi enemmän verrattuna kontrolliryhmään. Vajaaravitsemukseen liittyvä tiedontaso kasvoi tilastollisesti merkitsevästi enemmän koeryhmässä. Yhteydenottojen määrä poliklinikalle hoitosyklien välillä oli tilastollisesti merkitsevästi vähäisempää koeryhmässä verrattuna kontrolliryhmään.

Potilaan voimavaroja tukeva ohjaus saattaa parantaa suolistosyöpää sairastavien potilaiden tiedon tasoa ja aktivaatiotasoa. Se vähentää yhteydenottoja poliklinikalle ravinnon saantia heikentävien sivuvaikutusten vuoksi säästäen siten terveydenhuollon kustannuksia.

AVAINSANAT: hoitotyön vaikuttavuus, voimavaraistumista tukeva potilasohjaus, itsehoito, sivuvaikutukset, suolistosyöpää sairastava potilas

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Abbreviations

CBSM	Cognitive-behavioral stress management
CG	Control group
CI	Confidence Interval
CRC	Colorectal cancer
CTX	Chemotherapy
EPE	Empowering patient education
FACT-C	The functional assessment of cancer therapy-colorectal
IG	Intervention group
IQR	Interquartile Range
MD	Mean difference
MO	Data collection at baseline
MI	Data collection eight weeks after intervention
NICE	National Institute for Health and Care Excellence
NIS	Nutrition impact side effects
NRS2002	The nutritional risk screening tool
NRS	Numeral Rating Scale
PAM	The Patient Activation Measure
QoL	Quality of life
RasOma	Knowledge test of malnutrition and nutrition impact side effects
VR	Virtual reality
WHO	World Health Organisation

List of Original Publications

This dissertation is based on the following original publications, which are referred to in the text by their Roman numerals:

I Tuominen L, Stolt M, Meretoja R, Leino-Kilpi H. Effectiveness of nursing interventions among patients with cancer: An overview of systematic reviews. Journal of Clinical Nursing, 2019; 28:2401–2419.

II Tuominen L, Leino-Kilpi H, Meretoja R. Expectations of patients with colorectal cancer towards nursing care– a thematic analysis. European Journal of Oncology Nursing, 2020; 44, 101699.

III Tuominen L, Ritmala-Castrén M, Nikander P, Mäkelä S, Vahlberg T, Leino-Kilpi H. Empowering patient education on self-care activity among patients with colorectal cancer – a research protocol for a randomised trial. BMC Nursing, 2021; 20(1):94.

IV Tuominen L, Ritmala M, Vahlberg T, Mäkelä S, Nikander P, Leino-Kilpi H. The effect of nurse-led empowering education on nutrition impact side effects in patients with colorectal cancer undergoing chemotherapy: A randomised trial. Patient Education and Counseling, 2023; 107895.

The original publications have been reproduced with the permission of the copyright holders. The summary includes also previously unpublished material.

1 Introduction

When people are diagnosed with cancer, they receive tailored medical care, cancer survival being a key measure of the effectiveness. Effectiveness of nursing is a key element today in the care of patients with cancer due to increased morbidity which creates strain not only on those affected with cancer but also on health systems (Globocan 2020). In Finland, the number of patients in specialized health care outpatient clinics has increased by about 30 per cent over the last decade. At the same time when the demand for care is growing healthcare is struggling with a shortage of nurses. The necessary services will be produced with scarcer economic and human resources. (Ministry of Social Affairs and Health 2014, THL 2022.)

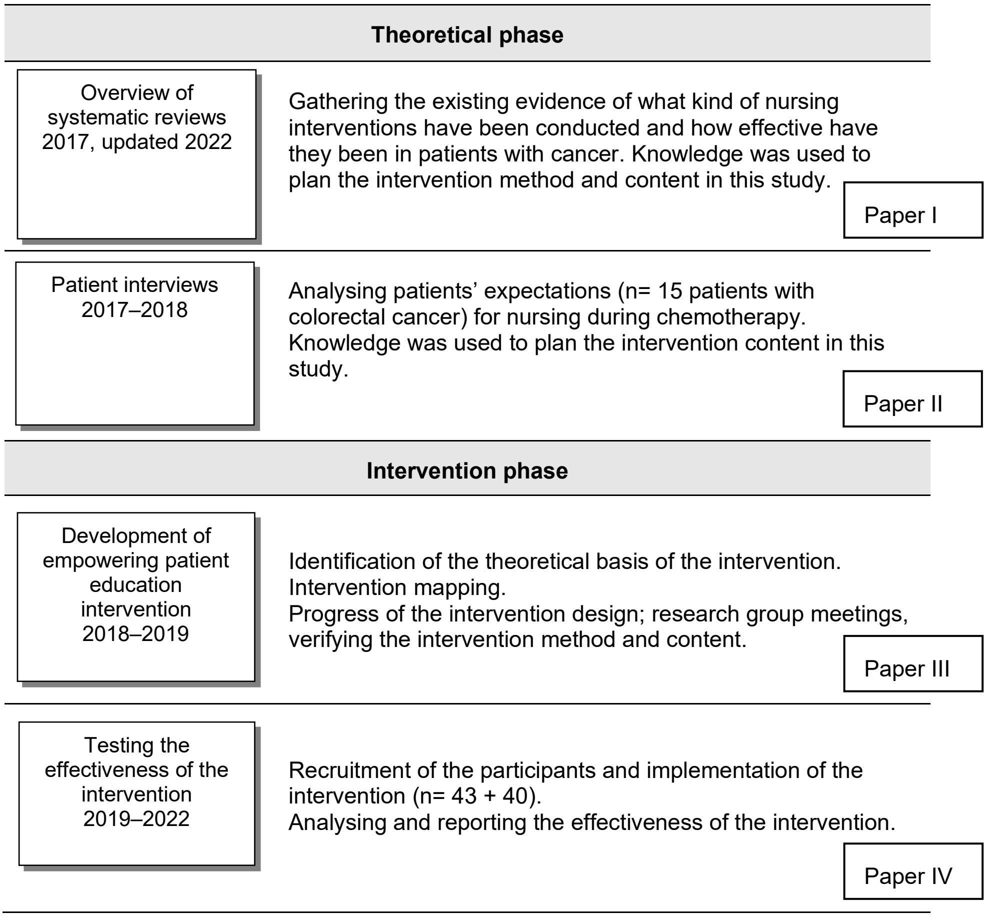
In Finland, the health care goal is to be effective in order to promote the well-being and health of the patient. Fair allocation of resources requires monitoring of the effectiveness of health care services (Kuntaliitto 2019). Further, the provision of health care should be based on evidence and recognised practices (1326/2010). One of the strategic goals in health care is to receive sufficient and effective services when needed. It also emphasises the development of health care services through evidence-based knowledge. (Programme of Prime Minister Sanna Marin's Government 2019.) In addition, the health care provided should be of high quality (Health Care Act 1326/2010) and patients' active role in own health must be supported (WHO 2015).

Patient participation seems crucial in enhancing the intervention effectiveness and thereby reducing dependency on health care professionals. Interventions with empowering characteristics have shown significant impact in improving patients' health and QoL. (Wallernstein 2006.) Today as the patients with cancer receive care mostly at outpatient clinics (THL 2022) the contacts with health care are short. Therefore, education on self-care plays a key role in health. In health care patient-centered approaches such as empowerment and participation are significant trends. They have increased patients' abilities to self-care, adopt healthier behaviours, and use health care services more effectively. (Wallernstein 2006.) Patient empowerment is related to awareness of own health situation and having an important role in managing own health (Tengland 2008, Fumagalli et al. 2015).

The aim of this two-phase study (Figure 1) was to produce new knowledge of the effect of empowering patient education in patients with colorectal cancer. The purpose was to (1) provide an overview of systematic reviews on nursing interventions and their effectiveness in patients with cancer; (2) describe comprehensively the expectations of patients with colorectal cancer (CRC) towards nursing; and (3) develop and test the effect of an empowering patient education of nutrition impact side effects on patient-reported outcomes and register data in patients with CRC.

This patient group was chosen because CRC is the second most common cancer type in men and women both in Finland and internationally (Globocan 2020). Furthermore, chemotherapy (CTX) may cause side effects such as nausea, fatigue, and diarrhoea, which may impair nutrition intake and cause risk of malnutrition. The complications of advanced malnutrition may impair quality of life (QoL) and the tolerance of CTX and ultimately, reduce overall survival. (Barret et al. 2011, van der Werf et al. 2018.) However, nursing studies related to nutritional interventions are scarce and have sought improvements merely in clinical outcomes, such as energy intake, nutritional status, and pre-albumin levels (Lin et al. 2017, Park et al. 2012, Xie et al.2017, Cate et al. 2020). Although the number of studies related to self-care in patients with cancer has increased over the years (McCorkle et al. 2011), few of them focus on patients with CRC.

The hypothesis was that those participating in empowering education have higher activation level, knowledge level of side-effects and their self-care, lower risk of malnutrition and higher quality of life compared to those who receive standard care. In addition, data of side-effects and their intensity, morbidity such as emergency room visits and additional contacts to outpatient clinic, and patient related treatment changes were collected.



Theoretical phase

Overview of systematic reviews 2017, updated 2022

Gathering the existing evidence of what kind of nursing interventions have been conducted and how effective have they been in patients with cancer. Knowledge was used to plan the intervention method and content in this study.

Paper I

Patient interviews 2017–2018

Analysing patients’ expectations (n= 15 patients with colorectal cancer) for nursing during chemotherapy. Knowledge was used to plan the intervention content in this study.

Paper II

Intervention phase

Development of empowering patient education intervention 2018–2019

Identification of the theoretical basis of the intervention.
Intervention mapping.
Progress of the intervention design; research group meetings, verifying the intervention method and content.

Paper III

Testing the effectiveness of the intervention 2019–2022

Recruitment of the participants and implementation of the intervention (n= 43 + 40).
Analysing and reporting the effectiveness of the intervention.

Paper IV

Figure 1. Phases of the study.

2 Review of the literature

In this chapter, the theoretical background and main concepts of the study are described. The main concepts of this study are effectiveness of nursing, patient expectations, empowering patient education, self-care, and patients with colorectal cancer. Related to theoretical phase, literature of nursing interventions and their effectiveness in patients with cancer and expectations of patients with cancer towards their care are presented. In addition, characteristics of patients with colorectal cancer and chemotherapy are presented. Related to intervention phase, empowerment is reviewed in relation to patient education and self-care. In the end, the main points of the literature are summarised.

2.1 Effectiveness of nursing interventions

In this study, nursing interventions refer to any activities taken by nurses to promote the well-being of patients with cancer. Nursing interventions are considered complex, which means that they may include multiple interacting components; for example, information and support. In addition, they may be connected on the context and behaviour of those delivering and receiving the intervention. Moreover, there is a range of possible outcomes to be measured. (Richards 2015.) When designing nursing interventions modifiable mechanisms underlying the target behaviour are identified to determine how the intervention will work. These mechanisms constitute the logic model of the intervention and may include changes in knowledge, beliefs, or skills, for example. (Abraham et al. 2015.) When assessing the effect of an intervention, effectiveness is connected with how much intervention is needed to obtain a certain level of effect (Hallberg 2015, Szalacha 2012). In statistical terms, establishing effect means explaining the variation in the dependent variable in relation to the intervention and the explanatory variables such as age, gender, and education (Hallberg 2015). A person's care and treatment is 'effective' when it is appropriate to their needs, delivered by the right person with the right skills and experience, in the right place, and at the right time. It is about doing something that will achieve a positive outcome and experience for the person (Care Quality Commission 2010). In this study, effectiveness of the intervention is defined as an ability to be successful and produce the intended results (Cambridge Dictionary

2021). When the effectiveness of the intervention is assessed from the patients' perspective, patient-reported outcome measures (PROMS) are used. It means a report directly from the patient, without interpretation by a researcher (CIHI 2015). Outcomes that are assessed by PROMs in clinical context should be relevant and feasible in the target population (Maio et al. 2022).

To explore the effectiveness of nursing interventions in patients with cancer, literature search was made in CINAHL and PubMed using terms (cancer patient) AND (nursing interventi*) AND outcome* OR effect* OR effic* and limiting the search for years 2007–2023, English language and adults. The literature revealed that effectiveness of nursing interventions among patients with cancer has been extensively studied internationally. Most interventions have focused on prevalence and severity of symptoms, especially during CTX and aimed at alleviating symptom distress. In most cases, interventions have included education, coaching and symptom assessment, but there have been considerable differences in the effectiveness of interventions. (Coolbrandt et al. 2014.) A brief theory-driven and individually tailored intervention managed to significantly decrease symptom distress of the patients during CTX. Tailoring focused on personal symptoms and self-management style, context, and dose of the intervention. Dose was one in-person coaching (30–60 minutes), one telephone-based coaching session (10-20 minutes), access to nursing service (telephone, e-mail) and additional coaching if necessary. (Coolbrandt et al. 2018.)

The effect of nursing interventions on QoL has been contradictory (Zhang et al. 2014). For example, an eight-week Self-management program for CTX-induced neuropathy symptoms had significant effect on symptoms and disturbances on daily living but not on improving QoL (Oh et al. 2022). The same result was seen with a Symptom management model which was delivered in six sequential weekly sessions (45 minutes in length) during CTX. It alleviated symptoms such as loss of appetite and insomnia, but no statistically significant difference was shown on QoL between intervention group (IG) and control group (CG) (Salvetti et al. 2021).

Intervention characteristics related to length, duration, and timing may contribute to its effectiveness. An intervention may be acceptable to patients but may not impact outcome variables if not delivered at the most appropriate time (Cook et al. 2014). For example, intervention consisting of writing about persons' deepest emotions and thoughts lasted 20 minutes for four consecutive days, which might have been insufficient for patients with cancer. No significant effect was found on psychological outcomes. (Oh et al. 2016.) In contrast, a six-month nurse-led self-efficacy enhancing intervention in patients with CRC significantly reduced symptom severity and interference in daily life in IG compared to CG (Zhang et al. 2014).

The mode of intervention may also have impact on interventions' effect. Telehealth interventions have become more common in recent years. In some cases, patients have preferred telephone follow-up compared to a regular visit to a doctor because it is easier for them (Cook et al. 2014). Telehealth interventions have demonstrated statistically significant effects on cancer-related symptoms such as fatigue and psychological symptoms, but the effect has been conflicting on QoL (Chen et al. 2018, Moretto et al. 2019, Xu et al. 2019). The effect of an intervention consisting of three telephone sessions with a handbook of symptoms and sleep management strategies during the 2.–4. week after the first CTX was non significant on fatigue, sleep and fuctional status. Authors presented various reasons for null effect, for example, intervention dose was considered too low. Another reason might have been that symptoms were not severe enough to show the improvement due to intervention. (Barsevick et al. 2010.) An online self-management education program which included five telephone-based coaching sessions to be completed within four months of CTX initiation significantly improved activation levels in IG whereas activation level decreased in CG (Howell et al. 2023). A multimedia tool in patient education which consisted of four meetings with one-hour nurse-led teaching session prior CTX and one follow-up call significantly increased knowledge level among patients with pancreatic cancer but not among the patients with CRC (Jabaley et al. 2020).

Although effectiveness of nursing interventions among patients with cancer have been comprehensively studied, some gaps in knowledge can be found. Only few of the studies have reported of the effect of nurse-led nutritional interventions among patients with cancer, yet the outcomes have been promising. In these studies, target of interest has been merely clinical, such as BMI, weight, albumin levels, energy, and protein intake (Rueda et al. 2011, Park et al. 2012, Lin et al. 2017, Xie et al. 2017, Cate et al. 2020). There is evidence that in particular, patients at risk of malnutrition benefit from nutritional interventions (Kondrup et al. 2003). In addition, prior studies of the effect of empowering education in patients with cancer are lacking, although empowerment is relevant to how patients develop their perception of the disease and its self-care (Vaartio-Rajalin & Leino-Kilpi 2011). Even though there is evidence of association between the QoL and the risk of malnutrition during the CTX (Calderon et al. 2019), evidence on the effect of brief interventions on QoL is scarce (Ryhänen 2012, Siekkinen et al. 2015).

2.2 Expectations of patients with colorectal cancer

In this chapter, patients' expectations towards nursing during chemotherapy are reviewed based on previous literature. According to the World Health Organisation (WHO 2023), patients should be at the heart of health care and supported in managing their own health. In Finland, patients' rights are defined in a law. The right to quality care (1992/785) means that patients' wishes, opinions, and individual needs are taken into account in the planning and implementation of care (2000/812). An essential component of ethical and safe care is to provide patients with appropriate information in line with their expectations. Patient education has an empowering effect when it is based on their individual expectations. (Vaartio-Rajalin et al. 2015). In intervention research, an empowering process means that patients participate in the development of the interventions (Zimmerman 1995). In this study, a patient-centred approach was adopted and patients' expectations for nursing care were taken into account in planning the content of intervention.

Literature was searched in PubMed and CINAHL in 2018 and updated in 2022 using the following search strategy: cancer patient* AND expect* OR desire OR preference, publication time frame 2008–2022, English language, academic journals, and adults. References of the articles supplemented the literature search (Paper II). Based on the earlier studies, care expectations of patients with cancer may be influenced by personal, situational, and clinical factors such as symptoms and distress. (Vaartio-Rajalin et al. 2014, 2015.) Expectations have focused on knowledge related to treatment, such as care alternatives, efficacy, prognosis, side effects and their management, as well as to sexuality (Rasmusson et al. 2013, van Weert et al. 2013, Tomball et al. 2014, Vaartio-Rajalin et al. 2015, Simacek et al 2007). Expectations have also focused on decision-making (Almyroudi et al. 2011) and support during the care (Kotronoulas et al. 2017).

It is noteworthy, that patients' expectations have varied at different phases of the care path. When initiating CTX, patients have not been quite aware what they should know, but later on have sought information perceived as important for them (Vaatio-Rajalin et al. 2015). At the end of CTX, patients expected to receive support in adapting to normal life and clarifying the roles and responsibilities of the follow-up plan. When cancer recurred, patients expected caring and compassion with optimism. In advanced disease, patients expected honest communication and support for hope. (Thorne et al. 2014.) When treatments have ended patients with CRC have expected to have tailored information and continuity in care (Beaver et al. 2010). Only a small proportion of distressed patients have been willing to accept emotional or psychological services (Merckaert et al. 2010, Baker-Glenn et al. 2011, Dubruille et al. 2015, Tondorf et al. 2020). Sometimes patients have expected to have more knowledge than received (Rankinen et al. 2007, Klemetti et al. 2015) or there have been discrepancies between nurses and patients as to which topics are considered important during the consultation (van Weert et al. 2013).

In previous studies, patients' expectations have been studied in terms of information, decision-making, and spiritual or psychological support. There have been studies in certain patient groups, such as patients with breast cancer, prostate cancer, and lung cancer. In addition, expectations of supportive needs have been studied, for example, among patients with CRC or cancer in general. However, there is a lack of studies, which focus on overall expectations of patients, such as cognitive, physical, psychological, and social aspects of care. Because patients with CRC represent one of the most common cancer types globally (Globocan 2020) and may face a long-lasting care with various CTX induced side effects, their care expectations may also be diverse and worth studies.

2.3 Empowering education in self-care

In this study, empowerment approach is used in patient education and empowerment is considered both as a process and as an outcome. The concept of patient empowerment is ambiguous with multiple definitions (Ellis-Stoll & Popkess-Wavter 1988, Gibson 1991, Rodwell 1996, Castro et al. 2016) and overlapping concepts, such as patient involvement, patient engagement, and patient enablement (Fumagalli et al. 2015). Most definitions describe empowerment as a power to influence one's own life (Leino-Kilpi et al. 1998, Fumagalli et al. 2015). Patient empowerment is related to a growing patient awareness of one's own situation and having an important task in the management and control of one's own health (Tengland 2008, Fumagalli et al. 2015). Patient empowerment is also related to the acquisition of power (Fumagalli et al. 2015) which is created in a partnership in which patients are willing to share power with a nurse, and in return, nurses share responsibilities with patients (Gibson 1991, Kuokkanen & Leino-Kilpi 2000, Aujoulat et al. 2007). Absence of power (Fumagalli et al. 2015) is related to lack of knowledge and loss of control (Castro et al. 2016). For example, patients may be disempowered in self-care because patient education is not performed at individual level (Vaartio-Rajalin et al. 2015). Knowledge is essential in empowerment (Leino-Kilpi et al. 1998, Anderson & Funnell 2010, McCorkle et al. 2011). Patients are empowered when they have the necessary knowledge to make decisions (Castro et al. 2016) and control their own actions (Fumagalli et al. 2015). Where there is power there is also knowledge and power increases through knowledge (Kuokkanen & Leino-Kilpi 2000, Fumagalli et al. 2015).

As a process, empowering education entails a patient-centered approach (Aujoulat et al. 2007, Tengland 2008, Castro et al. 2016) which takes into account patients' perspective related to expectations (Adolfsson et al. 2004), experiences, priorities, and fears (Aujoulat et al. 2007). It entails nurses' professional assessment (Anderson & Funnell 2010) and expert knowledge on how to achieve change (Gibson 1991, Virtanen et al. 2007, Tengland 2008). In empowering education patients become empowered in a dialogue, which encourages an active participation (Kuokkanen & Leino-Kilpi 2000, Radwin et al. 2009, Fumagalli et al. 2015, Castro et al. 2016). The role of healthcare professionals changes from dominant to supportive or facilitating (Wallerstein 2006), and from advisor to resource (Funnel et al. 1991). The empowerment approach entails that nurse acknowledge patients as being in control of their own care and health issues that they define as important (Gibson et al. 1991, Zimmermann 1995, Aujoulat et al. 2007, Tengland 2008, Anderson & Funnel 2010, McCorkle et al. 2011, Castro et al. 2016). During the process, patients become aware of their health problem (Gibson 1991, Zimmerman 1995), and are supported to find and use their own abilities to manage the health problem (Funnel et al. 1991). Empowering characteristics in a nurse-patient relationship are defined in terms such as equality, trust, security, warmth, co-operation, and mutual respect. The nurse-related characteristics are being a good listener and sensitive to 'missing information' (Gibson 1991, Kuokkanen & Leino-Kilpi 2000, Virtanen et al. 2007, Tengland 2008, Anderson & Funnell 2010, Fumagalli et al. 2015).

As an outcome, empowerment includes patients' ability to control their own health and health care (Wallerstein 2006, Fumagalli et al. 2015) and think critically and act autonomously in questions related to health (Anderson & Funnel 2010); for instance, adopt behaviour that sustains health and use health care services more effectively (Wallerstein 2006). Empowered patients may experience personal growth and development (Kuokkanen & Leino-Kilpi 2000, Castro et al. 2016). Empowerment can lead to improvements in QoL (Fumagalli et al. 2015, Castro et al. 2016) and self-care (Castro et al. 2016). A two-year randomised trial of diabetes self-management empowering intervention by Anderson et al. (2009) improved patients' QoL significantly but not their self-care behaviors. A trial by Collette et al. (2018) consisting of information brochure and use of patient diary revealed that surgical patients who were empowered had less severe pain and lower pain intensity. Empowering nursing interventions have resulted in significant improvements in patients' knowledge level, e.g., in ambulatory orthopaedic patients (Heikkinen et al. 2008) and in patients with breast cancer (Ryhänen et al. 2012). Similarly, they have improved patients' knowledge level in side effects' self-care in patients with breast cancer before radiotherapy (Siekkinen et al. 2015) and in patients with lumbar spinal stenosis surgery (Kesänen et al. 2016).

Patient empowerment and patient activation share the same features. Both activation and empowerment are related to increasing abilities, but also to patients' growing awareness that one can play an important part in self-care. Patient activation involves with knowledge how to manage health problems, self-care skills and motivation to participate in own health care. (Hibbard et al. 2004, Fumagalli et al. 2015.) Previously, increased activation has been associated with a positive change in self-care (Hibbard et al. 2007), which has decreased the number of hospital and emergency room visits, reducing healthcare costs (Greene & Hibbard 2011). Tailoring the intervention according to patients' activation level has led to improvements in activation, clinical outcomes, and also in health care utilisation

(Hibbard et al. 2009). In this study, education is perceived as an empowering process during which patients become aware of their health problems and self-care abilities and use the knowledge to make self-care decisions. It is also perceived as an outcome; patients who are empowered can control their own health and health care.

The terms self-care and self-management are often used for the same purpose. The concept of self-management has also been regarded both as a subset and an upper concept of self-care and is most frequently used in the context of long-term health problems (Richard & Shea 2011). However, self-management can be seen as a broader concept including the management of care, lifestyle changes and different consequences of the illness (Baydoun et al. 2018). Self-care is a situation-specific concept including health maintenance and monitoring and managing changes in health status when they occur (Riegel et al. 2019). In this intervention study, self care is seen as monitoring changes in health during chemotherapy and responding to chemotherapy induced side effects when they occur (Richard & Shea 2011, Riegel et al. 2012).

Self-care decisions made in everyday life are meaningful for the health and well-being of the patients with cancer for the following reasons. First, self-care enhances controlling chemotherapy induced side effects (Richard & Shea 2011) which have been found to affect a variety of health outcomes: QoL, functional status, psychological state, adjustment to illness, disease progression, and survival (Armstrong 2003, Richard & Shea 2011). Second, self-care may decrease health service utilisation and thus, reduce health care costs (Richard & Shea 2011).

2.4 Patients with colorectal cancer and chemotherapy

Patients with cancer were selected for the target group of this study and in particular patients with CRC as it is the third most commonly diagnosed cancer globally among both women and men. Each year about 1.9 million people are diagnosed with CRC and the number of new cases will increase by about 22.5% (rectum) and 27% (colon) (Globocan 2020a) during the years 2020–2040. In Finland, the amount of new patients has increased since the 1990s and CRC is now the second most common cancer type among males and females aged over 20 years. The incidence increases with age. In 2020, the number of new patients / 100,000 per year was 1645 in female and 1878 in male. (Finnish Cancer Registry 2020.)

Cancer, also referred to as neoplasm or malignant tumour, developes from the transformation of normal cells into tumour cells in a process where abnormal cells grow uncontrollably and may invade to other organs or parts of the body. This is called metastasising and it is a major cause of death from cancer. (WHO 2023.) Fortunately, improved treatments have led to more people with cancer living longer

(Phillips & Currow 2010). The harms caused by cancer on individuals and families may be physical, emotional, and financial (WHO 2023), which poses demands for nursing interventions as well.

Cancer treatment and care is multifaceted including surgery, anticancer therapy including CTX, and radiation therapy, either alone or in combination. CTX combined with other treatment modalities is common for patients with high-risk stage II and advanced CRC (NICE 2022). Intravenous chemotherapy is usually provided in an outpatient clinic every two or three weeks combined with oral medication at home. Until now, the standard duration of adjuvant CTX has been six months in patients with CRC, although shorter duration has also been suggested (NICE 2022). Despite the development of new types of therapies, the treatment may still cause a number of side effects for the patients, such as nausea, vomiting, diarrhoea, stomach pain, mouth sores, cold sensitivity, and loss of appetite as well as heartburn, alteration of taste and constipation (Pettersson et al. 2014, Röhrl et al. 2018, Schirrmacher 2019). These nutrition impact side effects may substantially change patients' nutrition intake. Moreover, the prevalence of side effects may remain at high level even 12 months following the commencement of CTX putting the patients at risk of malnutrition, which is associated with poorer QoL and thus, poorer overall survival (Tong et al. 2009, Hoffman 2013, Karabulut et al. 2021). Nurses working with patients with CRC must have insight into each patient's experience of their illness, care, and side-effects (Beets et al. 2017).

Although CRC is one of the most common types of cancer, there is a lack of nursing intervention research in this patient group (65 references in CINAHL) compared to patients with breast (328 references in CINAHL), lung (107 references in CINAHL) or prostate (84 references in CINAHL) cancer. In particular, there is a lack of nursing studies of empowering education in patients with cancer (Ryhänen et al. 2012, Siekkinen et al. 2015).

2.5 Summary of the literature

Main concepts of this study are effectiveness, patients' expectations, empowering education, self-care, and patients with colorectal cancer. In this study, effectiveness is defined as an ability to be successful and produce the intended results (Cambridge Dictionary 2021). In earlier studies, effectiveness of nursing interventions has studied extensively internationally. Most nursing interventions have focused on cancer and treatment-related symptoms, especially during CTX. In most cases, interventions have included education, coaching and symptom assessment, but there have been considerable differences in the effectiveness of interventions. In some studies, interventions' characteristics related to its mode, length, duration, and timing might have been contributed to its effectiveness (Cook et al. 2014, Oh et al. 2016).

There are some gaps in existing literature. Although anti-cancer treatment is tolerated better today than just a few decades ago, it can still cause numerous side effects that can substantially change patients' nutrition intake and lead to malnutrition. However, studies of the effect of nurse-led nutritional interventions among patients with cancer are scarce. In these studies, clinical outcomes (BMI, weight, albumin level) have been a target of interest (Park et al. 2012, Lin et al. 2017, Xie et al. 2017) rather than those reported by patients. Second, there is evidence of association between the QoL and risk of malnutrition during the CTX (Calderon et al. 2019) but research evidence on the effect of brief nursing interventions on QoL is limited (Ryhänen et al. 2012, Siekkinen et al. 2015).

This study relies on a patient-centred approach. Patients' expectations have been extensively studied, and the studies have focused on certain expectations such as knowledge, decision-making, and support. Some of the studies are conducted in certain patient groups, for example, patients with breast cancer (Almyroudi et al. 2011, Ryhänen et al. 2012) or prostate cancer (Tombal et al. 2013). There is evidence that patients' expectations vary during the care path (Vaatio-Rajalin et al. 2015, Thorne et al. 2014). However, there is a lack of studies focusing on expectations of patients as general taking account all aspects of care, especially in patients with CRC.

Empowerment is seen as patients being aware of their own health situation and having an important role in self-care and the health issues they define as important (Gibson et al. 1991, Zimmermann 1995, Aujoulat et al. 2007, Tengland 2008, Anderson & Funnel 2010, Fumagalli et al. 2015, Castro et al. 2016). In empowering education patients become empowered in a dialogue, which encourages an active participation (Kuokkanen & Leino-Kilpi 2000, Radwin et al. 2009, Castro et al. 2016). The nurse supports patients' empowerment in patient-nurse interaction, taking into account the patients' expectations for their care (Funnel et al. 1991, Wallerstein 2006). When patients are empowered in self-care, they become aware of being responsible for their own health-related decisions, have knowledge to develop self-care skills and control the factors affecting their health and achieve a desired goal they perceive as important (Tengland 2008, Fumagalli et al. 2015, Zimmerman 1995, Leino-Kilpi et al. 1998, Anderson & Funnel 2010). Self-care decisions made in everyday life are meaningful for the health of the patients with cancer. Self-care is perceived as monitoring for changes in physical and psychological side effects and willingness and ability to manage those changes when they occur (Richard & Shea 2011, Riegel et al. 2012). Prior studies of the effect of empowering education in patients with cancer are lacking, although empowerment is relevant to how patients develop their perception of the disease and its self-care (Vaartio-Rajalin & Leino-Kilpi 2011). Therefore, the intervention of this study was to be related to empowering education of nutrition impact side-effects and their self-care.

3 Aims of the study

This study aimed to produce new knowledge of the effect of empowering patient education in patients with colorectal cancer. In the theoretical phase (2017–2018), the purpose was first to provide an overview of systematic reviews on nursing interventions and their effectiveness in patients with cancer. Secondly, the purpose was to describe comprehensively the expectations of patients with colorectal cancer towards nursing. In the intervention phase (2018–2022), the purpose was to develop and test the effectiveness of an empowering patient education on patient-reported outcomes and register data in patients with CRC.

The research questions were as follows:

1. What kind of nursing interventions have been used in patients with cancer? Have they been effective? (Paper I)
2. What kind of expectations do the patients with CRC have for nursing during CTX? (Paper II)
3. What is the effectiveness of empowering patient education on patient reported outcomes and register data in patients with CRC? (Papers III and IV)

The hypotheses in testing the effect of the intervention were as follows (Paper IV):

Patients with CRC participating in empowering education *vs* standard education have

a) higher level of activation,
b) higher level of knowledge,
c) higher QoL, and
d) lower risk of malnutrition after a 2-month follow-up period.

4 Materials and Methods

In this chapter, the design, settings, sample, and data analysis of the study are described. A summary of the study phases and design of the substudies is presented (Figure 2). The study consisted of an overview of systematic reviews (Paper I) and patient interviews (Paper II) and empirical testing of the intervention (Paper III and IV). In theoretical phase, the overview of systematic reviews summarised what is already known about nursing interventions and their effectiveness in patients with cancer. Next, the interviews gave insight into the expectations of patients with CRC for their nursing during the CTX. The theoretical phase produced new knowledge which was used in planning the intervention method and content. In intervention phase, an intervention of empowering patient education was developed and finally tested empirically on patient activation level, knowledge level, risk of malnutrition and QoL in patients with CRC. Data was also collected of the side effects' prevalence and intensity (self-structured self-monitoring diary), emergency room visits, contacts to outpatient clinic, treatment interruption, transfer, and cancellation (register data).

I Theoretical phase (2017–2018)

Effectiveness of nursing interventions among patients with cancer - overview of systematic reviews (Paper I)

Research questions: What kind of interventions have been used to improve the effectiveness of nursing among patients with cancer? What was the effectiveness of these interventions?

Design, sample, and analysis: Overview of systematic reviews (n=17) with descriptive quantification and a narrative summary of the quantitative data.

Time: 2017–2018, 2021–2022.

Expectations of patients with CRC towards nursing care – a thematic analysis (Paper II)

Research question: What are the expectations of patients with CRC for nursing care during the chemotherapy?

Design, sample, and analysis: Individual interviews in patients with CRC (n=15) with thematic analysis.

Time and settings: 20 October–27 November 2017, University Hospital Cancer Center, Outpatient Clinic.

II Intervention phase (2018–2022)

Empowering patient education on among patients with colorectal cancer – a research protocol for a randomised trial (Paper III)

Research question: How the nurse-led empowering education using teach-back method will be tested on patient reported outcomes and clinical data among patients with colorectal cancer during chemotherapy?

The effect of empowering patient education in patients with colorectal cancer undergoing chemotherapy: A randomised controlled trial (Paper IV)

Research question: What is the effectiveness of empowering nursing education?

Design, sample, and analysis: A randomised controlled trial in patients with colorectal cancer (n= 43+40) with statistical analysis

Instruments:

- Knowledge level (RasOma, a self-structured instrument, Tuominen et al. 2021)
- Activation level (PAM, The Patient Activation Measure, Hibbard et al. 2004)
- The risk of malnutrition (NRS2002, The nutritional risk screening tool, Kondrup et al. 2003)
- The quality of life (FACT-C, The functional assessment of cancer therapy-colorectal, Cella et al. 1993)
- Number and severity of nutrition impact side effects (a self-structured self-monitoring diary)
- Emergency room visits, contacts to outpatient clinic
- Treatment interruption, transfer, and cancellation

Time and settings: 31 October 2019–11 March 2022, University Hospital Cancer Center, Outpatient Clinic.

Effectiveness of empowering patient education
in patients with colorectal cancer during chemotherapy

Figure 2. Study design, materials, and methods.

4.1 Design, setting and sampling in the theoretical phase

4.1.1 The overview of systematic reviews

The overview of systematic reviews was conducted in 2017 and updated in 2022 to summarise the findings of existing literature reviews addressing the effectiveness of nursing interventions in patients with cancer. It is a suitable method when plethora of reviews already exist on the subject (Becker & Oxman 2008, JBI 2014). The main objective was to produce strong research evidence on the subject and use the findings also in planning the method and content of the intervention in this study. For the development of the intervention, a broad review of the existing knowledge base was needed. (JBI 2014.) Overall, 1012 references were screened in CINAHL (407), Pubmed (308), Scopus (210) and Medline (97). The included systematic reviews (n = 17) were conducted in oncology settings in Australia (3), Belgium, Canada, China (4), Jordan, Korea (4), Spain, United Kingdom, and USA (Appendix 1, Paper I).

4.1.2 Interviews of patients' expectations

Descriptive research design was used to capture the expectations of patients with CRC for nursing during CTX (Paper II). Interviews produced knowledge about patients' expectations, which was also used for planning the intervention in this study. The interview was a suitable method because a previous study of the expectations of patients with cancer was limited and patients' experiences were target of interest (Parahoo 2006). In recruitment, purposive sampling was used, which involves selecting participants who have an experience in CRC and have the potential to provide rich and relevant data related to the research question (Tong et al. 2007). Patients (n = 15) were recruited during 20.10–27.11. 2017 from one out of five university hospitals in Finland due to its largest population area. Approximately 4,500 patients diagnosed with CRC receive CTX at the clinic annually. Eligible participants were adults (≥ 18 years) diagnosed with colon or rectal cancer, who were able to understand and speak Finnish, and were undergoing or had recently ended CTX in the outpatient clinic. Primary nurses in the outpatient clinic approached the eligible participants and informed the researcher, who arranged the interviews according to the patients' schedule. Of the 19 patients recruited, 15 agreed to participate in the study.

4.2 Design, setting and sampling in the intervention phase

An experimental longitudinal research design was developed to test the research hypotheses (Figure 3). To take into account patients' perspective, the results of patients' interviews (Paper II) were used in planning the intervention method and content for this study. Empowering knowledge of nutrition impact side effects and their self-care and support for empowerment in self-care comprised the content of the intervention.

In this study, we focus on the findings related to categories of educational interventions and interventions supporting patients' coping. The findings of the overview of systematic reviews were used in this study to plan the intervention of empowering patient education. According to the literature (Paper I) educational, psychological, psychosocial, and activity-based interventions and interventions supporting patients' coping were used in nursing of patients with cancer. In this study, we focus on the findings related to categories of educational interventions and interventions supporting patients' coping. Interventions were effective especially when they included several components. Previous literature showed that patient education that takes into account patients' individual expectations are effective (Vaartio-Rajalin et al. 2015). As a result, an educational intervention, during which patients' empowerment is supported in patient-nurse interaction and knowledge is shared of CTX induced nutrition impact side effects, was chosen. Patients' baseline activation level and self-monitoring data on side-effects was used to strenghten an individual approach to education. Nutrition was chosen because patients expected to have knowledge of nutrition impact side effects (Paper II). The experimental research design comprised a single-centre trial with a between-groups design and stratified randomisation according to disease prevalence and stoma. The effect was measured before and eight weeks after the intervention.

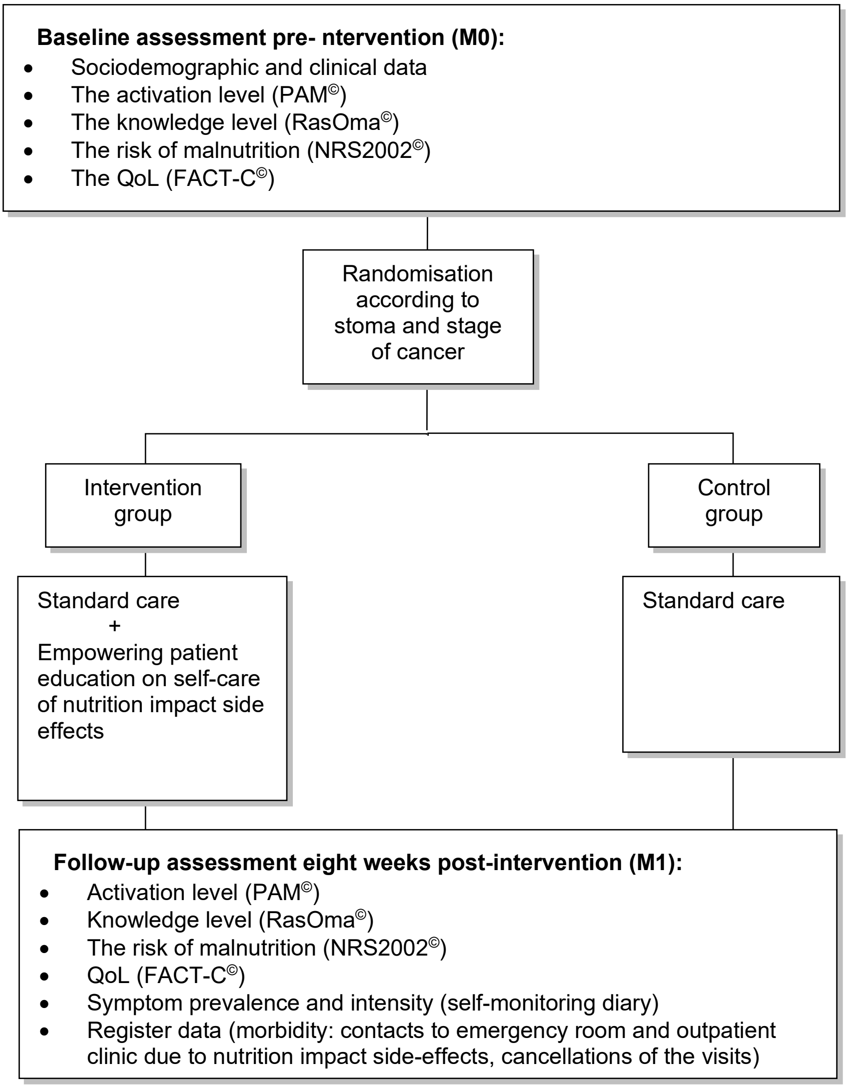
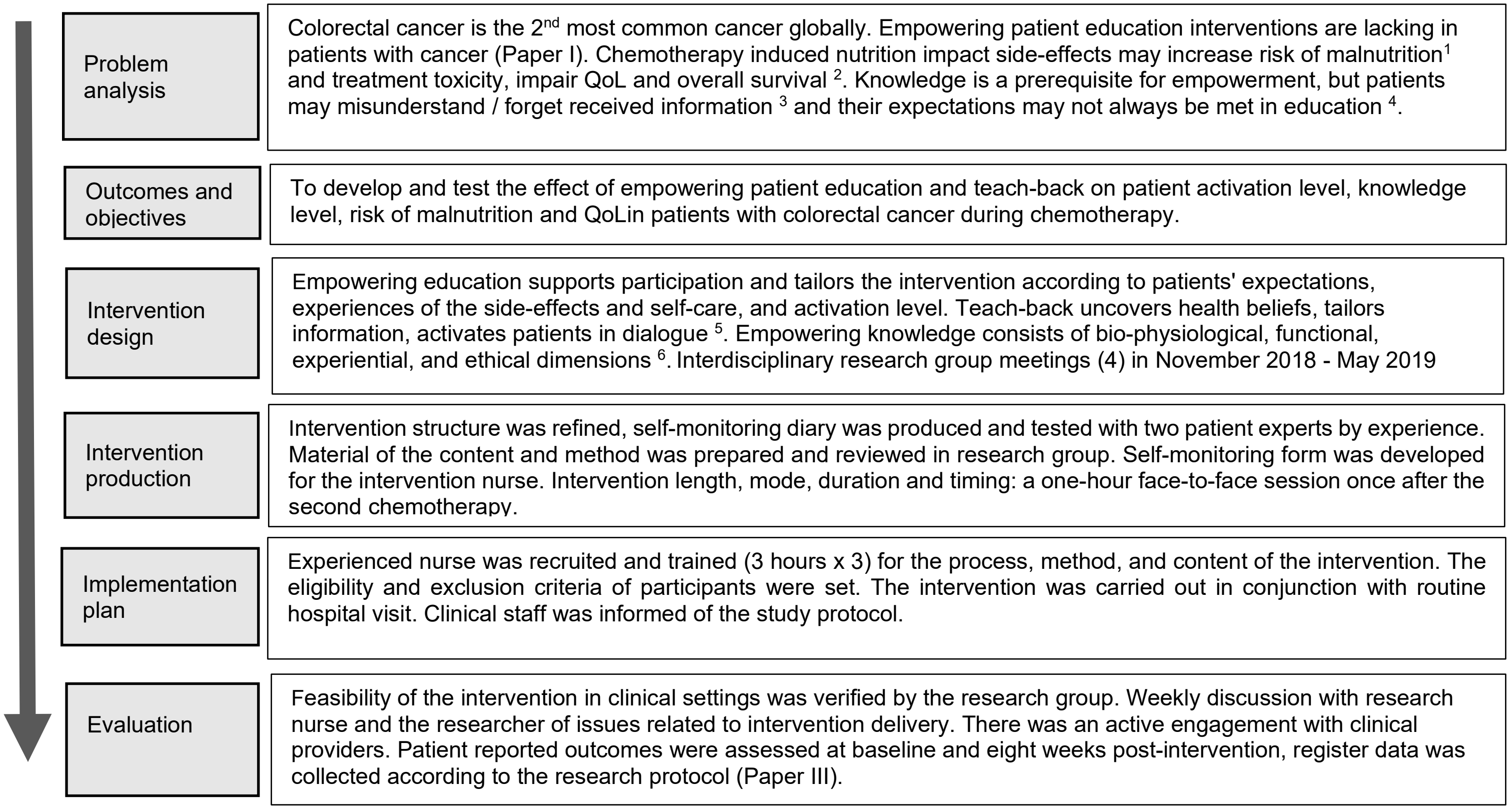


Figure 3. Intervention protocol (modified from Paper III).

The development of the intervention started in 2018 following the practical guide of Melnyk & Morrison-Beedy (2012) for designing and conducting intervention research. In addition, the intervention mapping approach was applied introduced by Bartholomew et al. (2016), which is a protocol for systematic theory-and evidence-based intervention planning. The approach instructs the application of theory- and evidence-based methods in the development of the intervention. (Kok 2014.) Next, the six phases of intervention mapping are first briefly presented (Figure 4) and described detailed (Table 1).



Problem analysis

Colorectal cancer is the 2nd most common cancer globally. Empowering patient education interventions are lacking in patients with cancer (Paper I). Chemotherapy induced nutrition impact side-effects may increase risk of malnutrition[1] and treatment toxicity, impair QoL and overall survival [2]. Knowledge is a prerequisite for empowerment, but patients may misunderstand / forget received information [3] and their expectations may not always be met in education [4].

Outcomes and objectives

To develop and test the effect of empowering patient education and teach-back on patient activation level, knowledge level, risk of malnutrition and QoLin patients with colorectal cancer during chemotherapy.

Intervention design

Empowering education supports participation and tailors the intervention according to patients' expectations, experiences of the side-effects and self-care, and activation level. Teach-back uncovers health beliefs, tailors information, activates patients in dialogue [5]. Empowering knowledge consists of bio-physiological, functional, experiential, and ethical dimensions [6]. Interdisciplinary research group meetings (4) in November 2018 - May 2019

Intervention production

Intervention structure was refined, self-monitoring diary was produced and tested with two patient experts by experience. Material of the content and method was prepared and reviewed in research group. Self-monitoring form was developed for the intervention nurse. Intervention length, mode, duration and timing: a one-hour face-to-face session once after the second chemotherapy.

Implementation plan

Experienced nurse was recruited and trained (3 hours x 3) for the process, method, and content of the intervention. The eligibility and exclusion criteria of participants were set. The intervention was carried out in conjunction with routine hospital visit. Clinical staff was informed of the study protocol.

Evaluation

Feasibility of the intervention in clinical settings was verified by the research group. Weekly discussion with research nurse and the researcher of issues related to intervention delivery. There was an active engagement with clinical providers. Patient reported outcomes were assessed at baseline and eight weeks post-intervention, register data was collected according to the research protocol (Paper III).

[1] Tong et al. 2009, Arends et al. 2017, [2] Karabulut et al. 2021, [3] Schillinger et al. 2003, Kripalani et al. 2008, Farris 2015, Peter et al. 2015, [4] Klemetti et al. 2015, [5] Schillinger et al. 2003, Farris 2015, Ha Dinh et al. 2016, [6] Zimmerman 1995, Castro et al. 2016, Leino-Kilpi et al. 1998, Leino-Kilpi ym. 2005.

Figure 4. The phases of intervention mapping (modified from Paper IV).

Table 1. The content of the intervention mapping.

Phase and content
Phase 1: Conducting a problem analysis Patients with colorectal cancer represent one of the most common types of cancer globally among both sexes. Intervention research conducted in this patient group (65 references in CINAHL) is scarce compared to patients with breast (328), lung (107) or prostate (84) cancer. Educational interventions have been effective in side effects' self-care but interventions of empowering education in patients with cancer are scarce (Paper I). Implementation of evidence-based methods in patient education is supported for mismatch between the information provided and desired is common in patients with cancer, e.g., information can be excessive, inappropriate, or difficult to understand (Joseph et al. 2017). Patients expected to be empowered with knowledge of chemotherapy induced side effects and their self-care (Paper II). The intervention focuses on self-care of nutrition impact side effects, as patients with gastrointestinal cancer may be at high risk of malnutrition (Arends et al. 2017). Nutrition-related nursing interventions with patient reported outcomes are scarce (Paper III). Previous research has focused merely clinical outcomes such as nutritional assessment, weight, energy and protein intake, and BMI (Cate et al. 2020). The target of change was patients' empowerement in self-care. Nutrition impact side effects may increase risk of malnutrition (Tong et al. 2009, Arends et al. 2017), impair QoL and overall survival in patients with colorectal cncer (Karabulut et al. 2021). The research group was established in autumn 2018 and consisted of two registered nurses, an oncologist, and a clinical nutritionist with extensive experience in oncology.
Phase 2: Intervention purpose and outcomes Purpose of an empowering education was to provide knowledge of chemotherapy induced nutrition impact side effects and their self-care using teach-back method and test its effect on patient reported outcomes. Primary outcomes were activation level and knowledge level. Secondary outcomes were risk of malnutrition and QoL. Register data was collected including side effects' prevalence and intensity, emergency room visits, contacts to outpatient clinic, treatment interruption, transfer, and cancellation. The hypothesis was that patients who participate in empowering education in IG have higher activation and knowledge level, less risk of malnutrition and higher QoL eight weeks after the intervention compared to standard care in CG (Figure 3).
Phase 3: Intervention design Active elements of the intervention are empowering patient education, self-monitoring diary and teach-back method. 1) Empowering education may enhance knowledge level (Kesänen et al. 2015, Siekkinen et al. 2015), self-care, and QoL (Castro et al. 2016). Empowerment is supported by establishing and maintaining an empathic connection, using active listening, encouraging patients to share their self-care experiences and ask relevant questions, supporting patients' belief in their own abilities to prevent and care for the side effects, and offering feedback of self-care methods that have already been successful (Virtanen et al. 2007). Empowering knowledge (Zimmerman 1995, Castro et al. 2016, Leino-Kilpi et al. 1998, 2005) includes following dimensions and content: a) bio-physiological knowledge: healthy diet (Finnish Food Authority 2014), dietary changes during chemotherapy, malnutrition and its prevalence and consequences in patients with colorectal cancer, and chemotherapy induced nutrition impact side effects and self-care methods b) functional knowledge: self-care methods and their effect and sources of additional knowledge

c) experiential knowledge: patients' experiences of side effects and self-care methods d) ethical knowledge: being valued and respected, patients' autonomy is supported if they decide to either change health behaviour or continue as usual based on the received knowledge (Gibson et al. 1991, McGormack & McCance 2017). Information is tailored to an individual level taking into account patients' activation level (Appendix 2), individual side effects, knowledge expectations and understanding (Figure 5). 2) It is important to check patients' understanding, for the received knowledge may not always be understood, or it may be forgotten (Schilling et al. 2003, Kripalani et al. 2008, Farris 2015, Peter et al. 2015). The teach-back method verifies patients' understanding, uncovers health beliefs, and encourages in dialogue (Schillinger et al. 2003). It has affected positively on self-care by improving the level of knowledge and self-efficacy and also reduced hospital readmission rates (Ha Dinh et al. 2016). Teach back is used by asking, for example: W*hat* is (malnutrition, nausea, etc.)? *Why* is it important to prevent or care (malnutrition, nausea, etc.)? *How* do you prevent or care (malnutrition, nausea, etc.)? Education material was primarily based on patient guidelines of the hospital (Paper III) but also on scientific literature and guidelines. The initial design was established by the researcher and verified by the research group in four shared and additional one-on-one meetings between November 2018 and May 2019.
Phase 4: Intervention production Multicomponent intervention consisting of empowering approach and teach-back was applied, for knowledge alone may not be effective in educational interventions (Paper I). Teach-back: Patients told in their own words the main components related to a) the knowledge of healthy diet and its variations during the chemotherapy, b) risk of malnutrition, c) nutrition impact side effects and their self-care methods. Empowering education: Applied as described previously in phase three and chapter 2.3. Timing: After the second chemotherapy cycle as participants were likely to have experiences of side effects and their self-care. Duration: a single session. Length: one hour. Mode: face-to-face.
Phase 5: Intervention implementation plan The settings were the same as in Paper II. Intervention nurse criteria was a long working experience of patients with colorectal cancer. The resource was 20 % of full-time-equivalent. The nurse was trained for the intervention process, method, and content by the researcher. The nurse's knowledge was assessed through a knowledge test and regular one-on-one discussions with the researcher. Recruitment of participants: The researcher recruited participants via patient records and contacted eligible candidates by letter and telephone. Willing participants were randomised and met for verbal information during the first chemotherapy cycle. Participants in IG were informed of the educational session after the second chemotherapy cycle. To support the intervention fidelity, the nurse reported after each session the duration, content, and use of teach-back. Clinical staff was informed of the study, i.e., nurses, nurse managers, and physicians in outpatient clinic at the beginning and in case of protocol changes (Munro 2012).
Phase 6: Evaluation Weekly reflections of intervention delivery (nurse and the researcher) Active collaboration with clinical providers such as care coordinating nurse, clinical nurses, nurse managers and oncologists to identify and solve proactively protocol-related issues, e.g., responsibilities and resource allocation. Outcome assessment: Activation level, knowledge level, risk of malnutrition and QoL were assessed prior to the intervention and eight weeks after the intervention.

In the intervention study, participants were recruited in the same settings as in the interview study (Paper II) during 31 October 2019–31 December 2021. Approximately 17–47 patients come in monthly for evaluation of CTX commencement in the outpatient clinic. Eligible participants were adults newly diagnosed with CRC and having oral or combination of intravenous and oral CTX. Exclusion criteria were impairment in functional capacity and insufficient comprehension of Finnish. To be empowered individuals need to be able to understand the meaning of health, process information, and act to promote their own health (Leino-Kilpi 2009). The sample size was calculated to detect a seven-point mean difference between the intervention and control groups in the PAM, assuming standard deviation of 11 points for both groups with 80 % power and 0.05 significance level. A total sample of 40 + 40 participants was considered to have power to detect the difference between the groups. (Paper III, IV.)

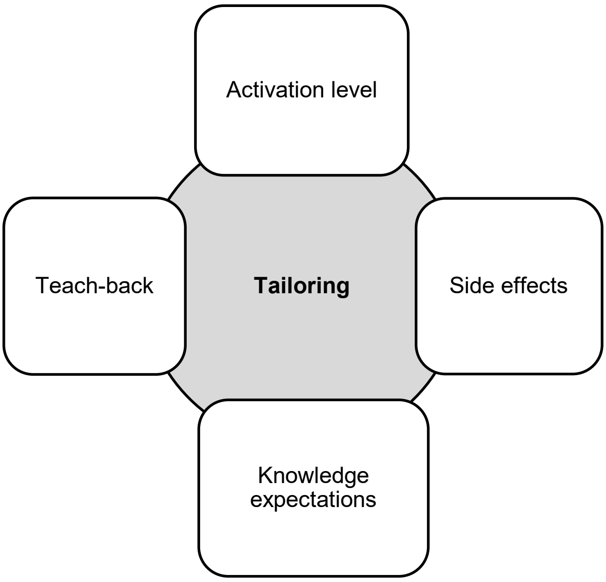


Figure 5. Elements in tailoring the intervention at an individual level.

4.3 Data collection

In this chapter data collection for the overview of systematic reviews, interviews, and intervention study is described. In overview of systematic reviews, the literature search was performed in 2017–2018 and updated in 2021–2022 for CINAHL, PubMed, Medline, and Scopus databases with the following combinations of key words: (cancer patient) AND (nursing interventi*) AND outcome* OR effect* OR effic* and tailored to each database. The time frame for published literature was

2007–2022. Two independent researchers confirmed the literature search and selection of studies was made based on eligibility criteria (Table 2) and quality assessment (Shea et al. 2009). A flow chart of the number of reviews identified, included, and excluded with reasons was documented (Appendix 1). Data collection entailed extracting relevant details and data from the included systematic reviews (JBI 2014) using a data extraction sheet developed for this study (Appendix 3).

Table 2. Eligibility criteria for systematic reviews.

Target	Inclusion criteria	Exclusion criteria
Population (P)	adults diagnosed with cancer	terminal ill, end-of-life care, age < 18 years
Intervention (I)	knowledge, education, exercise, psychosocial, psychological interventions	therapy (manual or invasive physiotherapy, massage) or complementary nursing, pharmacologic interventions, exercise as a main intervention
Comparators (C)	standard care, usual care, or general care	no control group
Outcomes (O)	effectiveness of intervention	examines solely outcomes due to the role of a nurse (e.g., APN, nurse navigator)
Study design (S)	review of intervention studies or RCTs	survey, observational, qualitative, case study, development project

In interviews (Paper II), data was collected during 20 October–27 November 2017 in a Unversity Hospital Cancer Center, Outpatient Clinic. The eligible participants were adults (≥ 18 years) diagnosed with CRC, receiving intra-venous CTX in outpatient clinic and able to comprehend Finnish language. Exclusion criteria were reduced cognitive, physical, or psychological function. Nurses at the outpatient clinic informed eligible patients of the study and those willing to participate gave written informed consent. Informants were interviewed during a standard outpatient visit. An interview guide based on previous studies (Vaartio-Rajalin et al. 2015) was used to keep the conversation on the desired themes (Polit & Beck 2021) which comprised of cognitive, psychological, spiritual, social, general, and concrete support expectations. The interviews lasted 30–90 minutes and were audiotaped upon informants' permission. They were continued until no new dimensions for categories could be identified (Holloway & Wheeler 2010).

In the intervention study (Paper III, IV), the effectiveness was tested in randomised controlled trial (Figure 3). Due to COVID-19 pandemic, changes were made in the protocol in spring 2020. First, the M2 measurement was omitted from the protocol due to prolonged recruitment. Second, the Ethics Committee approved a telephone survey to be used in data collection instead of a postal survey, if necessary. Third, due to virtual visits, the intervention was postponed by one week in connection with the second CTX. Finally, due to restrictions in Cancer Clinic, recruitment was paused for six months in 2020. Data was collected during 31 October 2019–11 March 2022, in a University Hospital Cancer Center, Outpatient Clinic. The primary outcomes of the intervention study were activation level and knowledge level, and secondary outcomes were risk of malnutrition and QoL. In addition, the number and severity of NIS was self-assessed. Morbidity was reported as emergency room visits and additional contacts to outpatient clinic due NIS. Patient-related treatment interruption, transfer, and cancellation was also monitored. The intervention was conducted after the second CTX when patients had experiences of treatment related side effects. The background factors asked were age, gender, education level, living conditions, employment, and dependents. Baseline data was collected before the patients arrived for their first treatment cycle (M0) and follow-up data was collected eight weeks after the intervention (M1) (Table 3) when the patients had experienced four treatment cycles, which was considered a sufficient period to assess the impact of the intervention. Next, the primary outcomes of the study are presented.

1) **Patient activation level** is seen as one aspect of patient empowerment. A lack of consensus and clarity remains about the constructs that measure patient empowerment (Barr et al. 2015, Castro et al. 2016, Eskildsen et al. 2017). In this study, the Patient Activation Measure (PAM, Hibbard et al. 2004) was used to measure components related to empowerment such as individuals' knowledge, skills, and confidence to manage their own health (Hibbard et al. 2005, Pekonen et al. 2020). The questionnaire consisted of 13 items on a 5-point Likert scale. Activation level was rated 1–4: 1 = low level, believing own role is important (scores ≤ 47.0); 2 = low level, having the confidence and knowledge to act for one's health (scores 47.1–55.1); 3 = moderate level, act to maintain and improve one's health (scores 55.2–67.0); 4 = high level, maintain health behaviour even under pressure (scores ≥ 67.1) (Hibbard et al. 2005, Insignia Health 2022). In previous studies, PAM has been shown to be a valid and reliable tool, which can be used in both tailoring nursing interventions and in assessing their outcomes (Hibbard et al. 2005, 2007, 2009, Insignia Health 2022) like in this study (Appendix 2).

2) **The knowledge level** was assessed because it is seen as crucial for empowerment (Castro et al. 2016). The knowledge related to malnutrition, NIS and self-care was measured with the knowledge test developed for the purpose

of this study (RasOma©, Tuominen et al. 2021). It comprised of biophysiological (four items of malnutrition, two items of side effects) and functional (nine items of side effects' self-care) knowledge dimensions (Leino-Kilpi et al. 1998). The items of the RasOma were generated based on the contemporary educational material of the cancer clinic and, in case the material was lacking, on scientific literature. The relevance of item content was confirmed in a research group consisting of two oncology nurses, an oncologist, a clinical nutritionist, and the researcher (LT). The face validity of the items was verified by two patient experts by experience and as a result, the wording of seven items was corrected. It is recommendated that the number of items should be limited to avoid burden on patients with cancer and to enhance patient participation (Maio et al. 2022). The RasOma included 15 items (Appendix 4). On a dichotomous scale a correct answer gave one point and an incorrect or missing answer zero points. The scores for correct answers establish the level of knowledge, higher scores indicating higher level of knowledge.

The secondary outcomes were the risk of malnutrition and QoL. Next, these outcomes are presented.

1) **The risk of malnutrition** was assessed because it is common in patients with CRC and CTX induced side effects may increase weight loss and the risk of malnutrition (Arends et al. 2017). The risk of malnutrition was assessed with the Nutrional Risk Screening Tool (NRS2002, Kondrup et al. 2003). The predictive and content validity of the tool has been evidenced in previous studies by Kondrup et al. (2003). In the NRS2002, patients score 0–7 points. Those with a total score of ≥ 3 are classified as being in a nutritionally high-risk category.
2) **The QoL** was measured because high QoL is considered to be a far-reaching consequence of patient empowerment (Castro et al. 2016). In this study, QoL is defined as individuals' perception of their position in life, in the context where their live and in relation to their own goals and expectations (WHO 2022). QoL was assessed with the Functional Assessment of Chemotherapy Treatment-Colorectal (FACT-C, Cella et al. 1993) designed to assess the QoL precisely in patients with CRC at all stages of the disease. In previous studies, the FACT-C has proved to be reliable and valid. Higher score indicates higher QoL: 34 points indicate low level, 34–68 points indicate satisfactory level, 68–102 points indicate average level and 102–136 points indicate high level (Ganesh et al. 2016, Goździewicz et al. 2017). In this study, the individual subscale scores were first calculated and summed to produce an overall QoL. The FACT-C was considered to be acceptable if > 50 % of the items were answered in the subscale

and the overall item response rate was > 80 % (Functional Assessment of Chronic Illness Therapy 2022, Ward et al. 1999).

In addition to primary and secondary outcomes, the following data was collected:

3) **Side effects prevalence and intensity** self-assessment was monitored to find out the effect of the empowering education on NIS with a self-monitoring diary developed for this study. The prevalence of side effects was documented, and their intensity was assessed on a numerical rating scale (NRS 0–10) before and after the self-care methods in IG and as it appeared in CG. Intensity was categorised as mild (1–4 points), moderate (2–7), and severe (5–10) using the cut-off points suggested by Given et al. (2008).
4) **Contacts to outpatient clinic and emergency room visits** (morbidity) were monitored. Worse nutritional status–in this study due to NIS–has been related to greater morbidity (Ravasco et al. 2012). Data was collected from patient records.
5) **Patient related treatment changes** i.e., cancellations and transfers of appointments, which were monitored to find out if empowering education is associated to compliance with the treatment schedule. Data was collected from patient records system during the research period.

Table 3. Collected data in the intervention study.

Outcome variable	Assessment	Instrument	Scale	Copyright owner
Patient activation	M0 M1	The Patient Activation Measure (PAM)	A 5-point Likert scale (disagree strongly…agree strongly) with 13 items. Four levels of activation in a 0–100-point scale: 1) Unready to take active role in own health, 2) lack of knowledge and confidence in self-care, 3) taking action but lacking confidence and skills to health supporting behaviours, 4) adopting health supporting behaviours, difficulties to maintain them under pressure	Hibbardt et al. 2004
The knowledge level	M0 M1	Ravinnon saantia heikentävät solunsalpaajahoidon sivuvaikutukset ja niiden omahoito (RasOma)	Dichotomous scale: yes / no with 15 items.	Tuominen et al. 2021
The quality of life	M0 M1	The Functional Assessment of Chemotherapy Treatment Colorectal (FACT-C)	A five-point Likert scale (not at all…very much) with 36 items on a subscale of physical wellbeing (0–28 points), social wellbeing (0–28 points), emotional wellbeing (0–24 points), functional wellbeing (0–28 points), and CRC subscale (0–28 points).	Cella et al. 1993
The risk of malnutrition	M0 M1	The Nutrional Risk Screening Tool (NRS2002)	Impaired nutritional status 0–3 scores (ability to eat, involuntary weight loss, body mass index, clinical state), severity of disease 0–3 scores and age 0–1 scores (< 70 years, > 70 years).	Kondrup et al. 2003
Morbidity	M1	Patients' records	Number of emergency room visits and additional contacts to outpatient clinic	
Compliance with the treatment schedule	M1	Patients' records	Number of cancellations and transfers of appointments	
Side effects prevalence and intensity	M1	Self-monitoring diary	Numeral rating scale 0–10 (0 = not at all, 10 = the worst possible)	

4.4 Data analysis

In this chapter data analysis for the overview of systematic reviews, interviews, and intervention study is described. In the overview of systematic reviews, the results were presented by using descriptive quantification and a narrative summary (Paper I). The syntehesis focused on whether the intervention was beneficial, whether no difference existed between the intervention and control groups or whether it was less effective compared to standard care (JBI 2014, Appendix 5). The methodological quality of the systematic reviews was assessed with AMSTAR appraisal tool for systematic reviews (Shea et al. 2009, Ryan et al. 2014).

In the interviews, thematic analysis was used to identify, analyse, and report the data (Braun & Clarke 2006). After reading thoroughly transcribed texts, initial codes were generated according to their meaning and grouped in accordance with their content into potential themes with the help of tables and thematic maps (Figure 6). Analysis focused on semantic level without examining the latent content of the data. The authors (LT, HL-K, RM) reviewed preliminary themes, which were refined and finally named. (Paper II.)

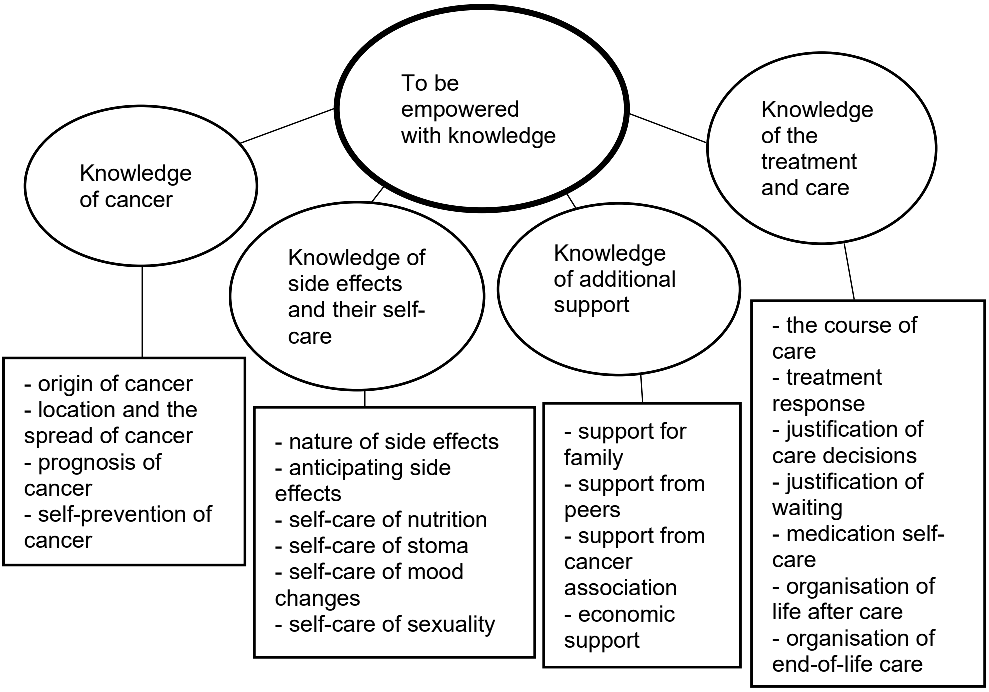


Figure 6. Thematic map of the theme 1.

In the intervention study, the analysis of quantitative data included statistical analysis and comparison of change in primary and secondary outcomes between the IG and CG at baseline and eight weeks after the intervention (Table 3). Categorical variables were described with frequencies and percentages. Continuous variables were described with means and standard deviations (normally distributed variables) and with medians and interquartile ranges (non-normally distributed variables). The differences in changes between IG and CG in continuous outcomes were compared with two-sample t-test (normally distributed outcomes patient activation and the quality of life) and Mann-Whitney U-test (skewed distributed outcomes the risk of malnutrition and knowledge level). A general linear model (GLM) was performed to explore the association of demographic and clinical factors with normally distributed outcomes after adjustment for group. Bonferroni correction was used in adjustment for multiple comparisons. Mann-Whitney U-test and Kruskal-Wallis test were used to analyse the association of demographic and clinical factors with the outcomes with skewed distribution. The Pearson correlation factor was used to calculate whether the baseline activation level was associated with change in activation level after the intervention. P-values less than 0.05 were considered statistically significant. (Paper III, IV.) Data analysis was performed using IBM SPSS 25.0 for Windows (IBM Corp., Armonk, NY).

4.5 Ethical considerations

This work followed the principles of the Declaration of Helsinki (WMA 2013). The phases of this study were designed, conducted, and analysed according to the scientific principles of the Finnish National Board on Research Integrity (TENK 2019) and were reported in international peer reviewed nursing journals.

The overview of systematic reviews was reported according to the PRISMA guidelines. Ethical approval was not necessary. The systematic method verified that all available studies meeting the inclusion criteria were selected. Two researchers were working together to confirm the research results. (Paper I.)

The interview study was given the ethical approval by the organisation’s Ethics Committee in June 2017 (Research organisation /1788/2017) and the research permit was granted in October 2019 (Research organisation /238/2017). The study was explicitly and comprehensively reported according to the consolidated criteria for reporting qualitative research (COREQ) (Tong et al. 2007). Patients’ health, well-being and rights were protected through voluntary participation, which was allowed to be suspended at any time without explanation (WMA 2013). Written informed consent was obtained from the study participants both verbally and in writing. Privacy was ensured by interviewing the participants in a private space. Participation did not cause extra expenses or hospital visits to the participants. Anonymity and confidentiality of information was protected by storing the data in password-protected computer files, managing it confidentially, and discarding it after analysis. (Paper II.)

In the intervention study, the development of the protocol was conducted with respect for human rights, safety, and wellbeing. The design of the research protocol followed scientific criteria and was reported by using the SPIRIT Statement (Chan et al. 2013), clear inclusion and exclusion criteria and randomisation (ICH 2019). The study protocol was registered on 9th of November 2019 (NCT04160650) and published in a scientific nursing journal in 2021 as the recruitment of participants was ongoing. In the development of the RasOma knowledge test and self-monitoring diary, patients' views were requested to provide the perspective of those who had experienced CRC. Permission to use the other instruments was obtained from the copy-right holders or from those who had developed the instrument. The content of the intervention was validated in an interdisciplinary group of health care professionals experienced in oncology. The intervention relied on evidence-based knowledge and individual experiences of the patients. During the empowering education, existing relevant guidelines of the organisation were used, thus the knowledge was reliable. (Paper III.) As nurses do not have the right to change the cognitive structures of other people, the research nurse was to provide support for patients to find and use their own resources in self-care and respect their individual experiences (Leino-Kilpi 2009).

The randomised controlled trial (Paper IV) followed the CONSORT statement for reporting parallel group randomised trials (Moher et al. 2010). The research was given ethical approval by the organisation's Ethics Committee (Research organisation /2115/2019) in September 2019. The study participants gave their written informed consent. The research nurse delivering the intervention had extensive experience in oncology nursing, including patients with CRC, and was trained for the intervention in terms of its content and methodology (WMA 2013). The confidentiality of information was protected by storing the data in password-protected computer files. In addition to the researcher, the data was accessible to the research nurse during the recruitment and while implementing the intervention and to the statistician during the analysis phase. The electronic files will be destroyed after the publication of the doctoral thesis. During recruitment, the protocol was simplified to enhance the feasibility of the study in clinical settings and to allocate healthcare resources to critical areas. First, the roles of the physician and care coordinating nurse were waived. Second, from spring 2020, the researcher recruited participants herself instead of a research nurse, whose 20 % working hours were devoted to implementation of the intervention. Third, the timing of the intervention was changed due to the COVID-19 pandemic. During the study, the design was assessed continuously to ensure that the planned activities were appropriate and necessary (ICH 2019).

5 Results

In this chapter, the results of the overview of systematic reviews, interviews and intervention study are reported. The main results of the study are briefly summarised in the end of this chapter.

5.1 Effectiveness of nursing interventions in patients with cancer

The overview of systematic reviews (Paper I) produced new knowledge of interventions and their effectiveness in patients with cancer. Nursing interventions have been complex due to their several components and outcomes. In overview of systematic reviews, five intervention categories were identified (Figure 7): educational, psychosocial, psychological, and activity-based interventions and interventions supporting patients' coping. All these nursing interventions included an educational aspect. The methodological quality of the systematic reviews was assessed as high in 13 and medium in four reviews according to AMSTAR appraisal tool for systematic reviews (Shea et al. 2009, Ryan et al. 2014).

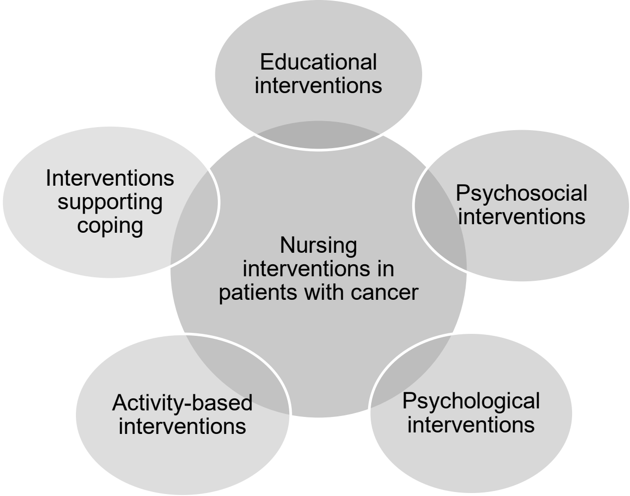


Figure 7. The nature of nursing interventions in patients with cancer (Paper I).

Educational nursing interventions

According to the overview of systematic reviews, educational nursing interventions (n = 7) have consisted of information provision, guidance, coaching and counseling (Cook et al. 2014, Coolbrandt et al. 2014, Zhou et al. 2015, Xu et al. 2019, Ream et al. 2020, Kim et al. 2021), and behaviour management (Xu et al. 2019) but also of support and encouragement (Hersch et al. 2009). The effects of nursing programs and preoperative educational interventions have been statistically significant on patients' knowledge level (Zhou et al. 2015, Kim et al. 2021). The effects of educational interventions on cancer-related symptoms have been studied widely. Positive effects have been found with individually tailored educational interventions (Hersch et al. 2009, Cook et al. 2014) on uncertainty of patients with gynaecological cancer. In many studies the intervention effect on symptom burden has been conflicting; e.g., the number of symptoms has reduced but the effects on symptom prevalence have seldom been statistically significant. Reduction in symptom severity has varied considerably at patient level, being 7–67 %. (Coolbrandt et al. 2014.) Furthermore, the effects on physical symptoms such as pain, dyspnea, and fatigue have been contradictory (Ream et al. 2020). Conflicting effects have also been found on psychological symptoms such as distress (Hersch et al. 2009, Coolbrandt et al. 2014), anxiety (Hersch et al. 2009, Cook et al. 2014, Ream et al. 2020), uncertainty (Ream et al. 2020), and depressive symptoms (Hersch et al. 2009, Rodin et al. 2007, Ream et al. 2020, Cook et al. 2014, Kim et al. 2021), although beneficial effects on depressive symptoms have also been found (Zhou et al. 2015). The effect of educational interventions has been statistically significant on the QoL of patients with gynaecological cancer (Cook et al. 2014). In contrast, non-significant effects on QoL have been found with e-health interventions (Xu et al. 2019), educational nursing programmes (Zhou et al. 2015), and preoperative (Kim et al. 2021) and individualised discussions (Hersch et al. 2009). In the original studies of the overview of systematic reviews the characteristics of educational interventions have varied in the number (1–30) and length of sessions (15 minutes–three hours). The duration of the interventions has ranged from one appointment to 13 months.

Psychosocial interventions

According to the overview of systematic reviews, psychosocial interventions (n = 4) consisted of spiritual and existential interventions (Oh & Kim 2014), expressive writing (Oh & Kim 2016) and psychological and social aspects (Son et al. 2018) and virtual reality technology (VR) (Ahmad et al. 2020). The effects of spiritual interventions have been moderate on spiritual well-being, meaning of life and depression. The effect has been significant on anxiety but moderate on meaning of life (Oh & Kim 2014). Interventions consisting of expressive writing relieved cancer-related symptoms and fatigue, pain, and sleep disturbance, but non-significant effect was shown on psychological and cognitive outcomes (Oh & Kim 2016). Intervention including psychological and social aspects i.e., cognitive behavioral therapy, counselling, and social skills' training, had non-significant effect on QoL (Son et al. 2018). Intervention using immersive (the participant does not observe the outside world but becomes absorbed by playing only) type of virtual reality (VR) significantly reduced anxiety and pain during chemotherapy and hospital stay in elderly patients with advanced cancer. VR reduced significantly pain and anxiety compared to morphine alone (Ahmad et al. 2020). Psychosocial intervention sessions have varied in the number (1–18) and length (15 minutes–1,5 hours) and duration of the interventions has ranged from 2 days to 16 weeks.

Psychological interventions

According to the overview of systematic reviews, psychological interventions (n = 2) have consisted of cognitive–behavioral and supportive forms of therapy. Psychological interventions had a statistically significant effect on cancer-related fatigue especially with group-based interventions. (Jacobsen et al 2007.) Cognitive-behavioral stress management showed conflicting findings on psychological outcomes such as anxiety, depression, but significant effects on mood and serum cortisol. Non-significant effect was found on stress. (Tang et al. 2020). The number of intervention sessions were not reported in these studies. Length of sessions was two hours and duration of the interventions ranged from 10 to 20 weeks.

Activity-based interventions

According to the overview of systematic reviews activity-based interventions (n = 2). They have included exercise recommendations as well as different type (e.g., aerobic or resistance) and mode (e.g., walking or cycle ergometer) of interventions against cancer-related fatigue. Non-pharmacological interventions may prevent or relieve cancer-related fatigue especially in patients with breast cancer and home-based programs. (Jacobsen et al 2007). A review of Rueda et al. (2011) assessed the effect of non-invasive interventions - including exercice - in symptoms, psychological functioning and QoL in patients with lung cancer and found a beneficial effect on empowerment and on muscle strength but not in QoL. Number and length of intervention sessions and duration of the intervention were not reported.

Interventions supporting patients' coping

The heterogeneous group of interventions (n = 5) was categorised as interventions supporting patients' coping. Alongside education they included various components such as emotional, psychological, and social, (Cook et al. 2014), physical and practical aspects (Rueda et al. 2011, Cook et al. 2014). In these interventions, nurses encouraged patients to rebuild appropriate strategies to strengthen hope and find meaning in life-threatening illness, as well as supported patients' ability to cope with cancer in meaningful ways (Li et al. 2018). Some of the strategies included forgiveness and dignity therapy (Li et al. 2018) and a problem-solving approach (Li et al. 2018, Rodin et al. 2007) as well as monitoring and coordinating care (Rodin et al. 2007). Furthermore, patients were trained on rehabilitation techniques and coping strategies and offered emotional and psychological support. Some of the interventions consisted of anxiety management and reflexology as well as more concrete methods such as nutritional components, exercise (Rueda et al. 2011) or telephone-based physical activity, emotional expression, and symptom management (Zhang et al. 2018). The effect of interventions supporting patients' coping was statistically significant on QoL (Cook et al. 2014, Zhang et al. 2018), on psychological symptoms such as depression (Rodin et al. 2007) and anxiety, but not on fatigue (Zhang et al. 2018) except in patients with lung cancer. Rehabilitation techniques combined with emotional support had benefits on distress, anxiety, and dyspnoea (Rueda et al. 2011). Moreover, the interventions supporting patients' coping have significantly improved the level of hope (Li et al. 2018) and the ability to cope with cancer (Cook et al. 2014). The interventions supporting patients' coping including exercise were beneficial on empowerment in patients with lung cancer. Interventions targeting nutritional improvements (Rueda et al. 2011) were effective on caloric intake, but a limited effect was shown on weight. The length of the interventions supporting patients' coping ranged from 10 to 120 minutes. The number of sessions varied from 1 to 6 sessions a week and duration of the intervention ranged from 6 weeks to 13 months.

5.2 Patients' expectations towards nursing

In this chapter, the findings of the thematic analysis of the interviews are summarised. The results are presented in detail in Paper II. In this study, patients with CRC (n = 15) were interviewed about their expectations for nursing during the CTX. According to the thematic analysis patients expected to be empowered with knowledge, humanely encountered, and skillfully cared for (Figure 8).

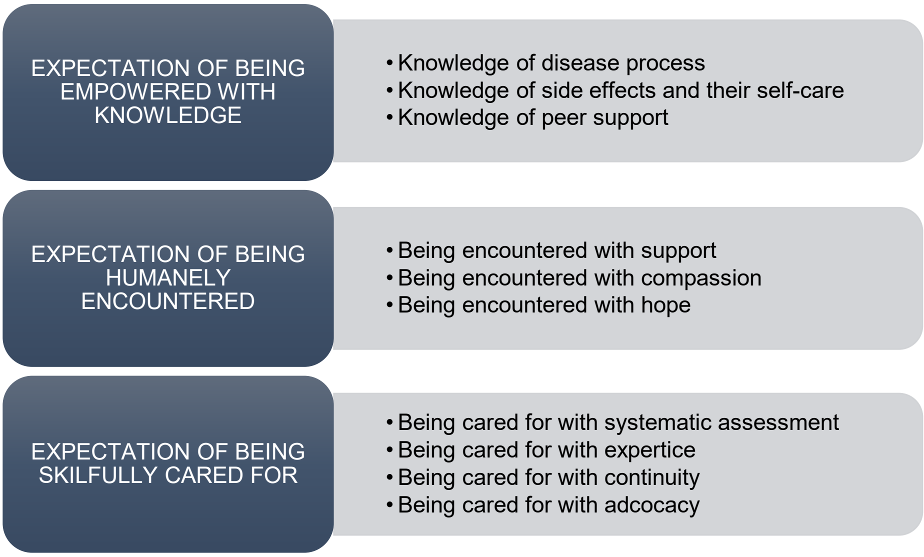


Figure 8. Patients' expectations for nursing during the CTX (modified from Paper II).

The first theme, expectation of being empowered with knowledge, included knowledge of the disease, side-effects and their self-care, and peer support. Knowledge expectations for the disease process included, e.g., treatment and its efficacy, care-related decisions, and side effects. With regard to side effects, patients expected to receive consistent information of NIS to ensure adequate nutrition intake during the CTX. Information of peer support was particularly highlighted in those with advanced disease or upcoming major surgery, although peer support was sometimes also perceived as distressing.

The second theme, expectation of being humanely encountered, comprised expectation of being encountered with support, compassion, and hope. Support consisted of encouragement, which was described as the nurse being honest but at the same time sustaining hope. It also included the nurse being a back-up in exceptional care situations. In addition, patients expected to be supported in order to live one day at a time. Patients expected nurses' compassion and genuine interest in encounters, which alleviated anxiety and gave an inner peace. Hope manifested itself as being cured of cancer, living a normal life and being confident in the future. Hope was expected to be present in all encounters with health care workers.

The third theme, expectation of being skilfully cared for, included expertise, care assessment, continuity, and advocacy during the CTX. The care assessment included reviewing the care plan together and assessment of how the patient is coping with cancer. Consultation with a clinical nutritionist and social worker were expected to be a part of the routine care. The expectation of being cared for with expertise consisted of trust and straightforward conversation with a nurse, including active listening. As part of continuity, patients expected to be cared for by the same nurse during the CTX. In practice, it meant knowing the individual aspects of the care as well as being able to reach the nurse between treatment cycles if necessary. Advocacy took place, for example, with the nurse acting as an intermediary between the doctor and the patients.

5.3 The effect of empowering education in patients with colorectal cancer

In this chapter the results of the intervention study are presented according to the research hypotheses. In the last chapter, the main results are summarised. The results are presented in detail in Paper IV.

5.3.1 Characteristics of participants in intervention study

In the intervention study, a total of 396 patients were assessed for eligibility; of them 37 declined to participate and 128 met the inclusion criteria. Of these, 65 patients were randomly assigned to IG and 63 to CG; of these, 43 + 40 participants completed the measurements both at baseline and eight weeks post-intervention. The drop-out rate was 33.85% and 36.50%, respectively. In IG, reasons for discontinuing were as follows: treatment was not started (1), treatment was interrupted (3), refused (1), weak functional ability (2), death (2), not reached (3), and lost to follow-up (10). In CG, reasons for discontinuing were as follows: treatment was not started (2), refused (7), and lost to follow-up (14).

The baseline clinical and demographic characteristics of the participants did not differ between the groups. Participants were mainly over 60-year-old males and females (Figure 9). More than 70% were diagnosed with colon cancer and most of them had had prior surgery (88%). More than half (54%) of the participants had advanced CRC that had spread to other parts of the body. As anticancer medication, chemotherapy with palliative or curative intent was used; in metastatic disease it was combined with immunotherapy.

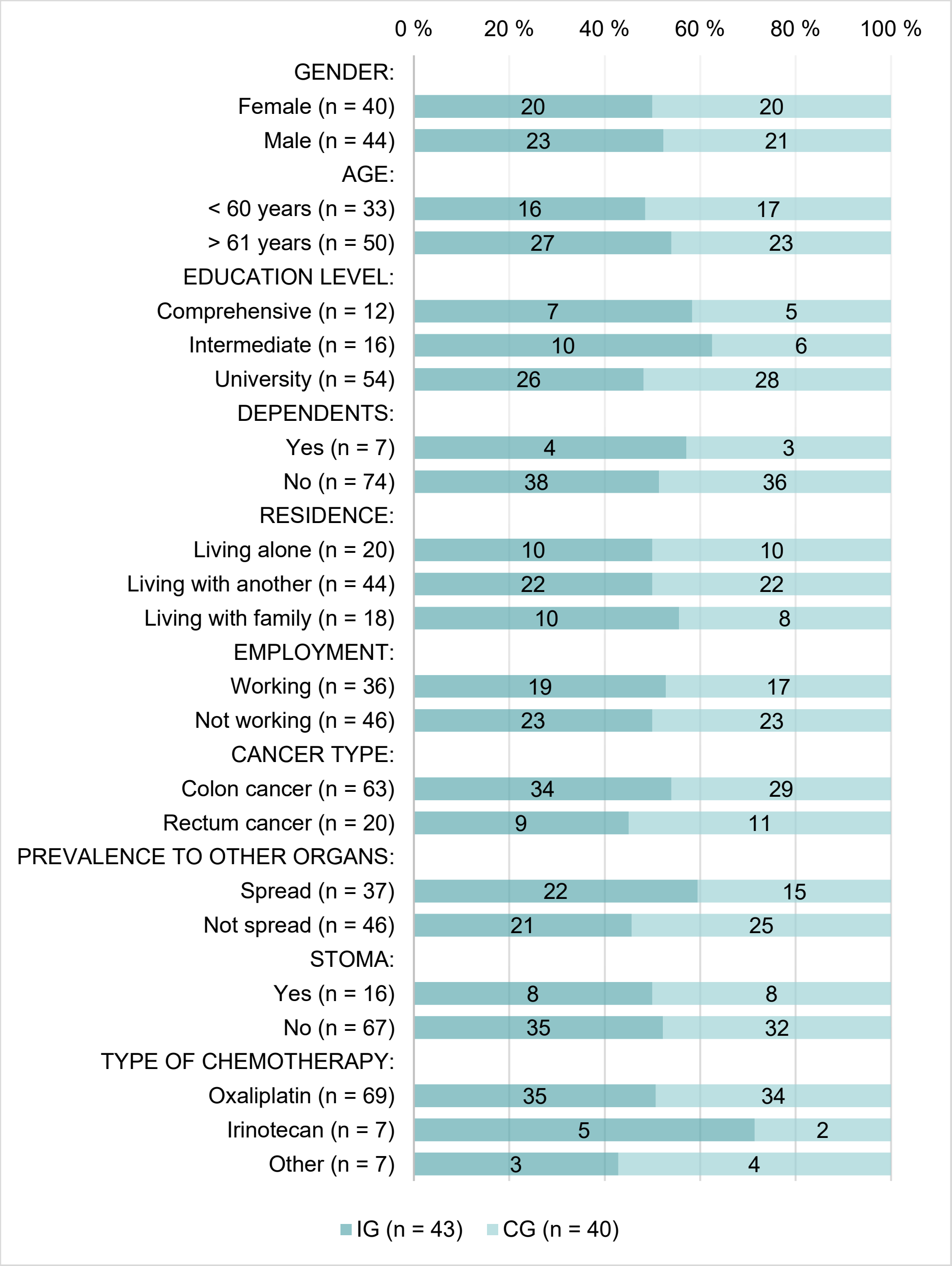


Figure 9. Demographic and clinical characteristics of the participants (n = 84).

5.3.2 Effectiveness of the intervention

In this chapter, the outcomes of the intervention are presented according to the research hypotheses. The baseline and follow-up scores and change in outcomes are presented in detail in Paper IV (manuscript) and in summary (Appendix 6).

Patient activation

The hypothesis was that activation level is higher in those who participated in empowering education (IG). At baseline, mean patient activation scores suggested moderate activation level in IG and CG (56.7 and 59.6, respectively). After the intervention, a positive trend in the change in activation level was detected between the groups favouring the IG (MD 4.45, 95% CI–0.19 to 9.09, $p = 0.060$) (Figure 10). Baseline activation scores did not correlate with the change in scores after the intervention in IG ($r = –0.06$, $p = 0.70$) indicating that tailoring the education according to participants' activation level did not enhance the effect of the intervention (Figure 11).

Knowledge level

The hypothesis was that knowledge level is higher in those who participated in empowering education (IG). At baseline, the median knowledge level was high in both IG and CG (13.0 and 14.0, respectively). After the intervention, there was a statistically significant increase in the change in malnutrition-related knowledge level in IG (median 0.0, IQR 1.00) compared to CG (median 0.0, IQR 0.0, $p = 0.028$). Statistically non-significant change in overall knowledge level between the groups was seen (median 0.0, IQR 2.00 vs median 0.0 IQR 1.9) (Figure 12).

The risk of malnutrition

The hypothesis was that the risk of malnutrition is lower in those who participated in empowering education (IG). At baseline, the risk of malnutrition was not present in IG and CG, (median 1.0, IQR 1.00 vs median 2.0, IQR 2.00 respectively) and M1 (median 1.5, IQR 1.00 vs median 2.00, IQR 1.00) . When comparing the change in the risk of malnutrition, no significant difference between the groups was found (median 0.0, IQR 1.00).

The QoL

The hypothesis was that QoL is higher in those who participated in empowering education (IG). At baseline, QoL was at high level in both IG and CG (104.8 and

106.9, respectively). A negative change in QoL was seen in both groups after the intervention (mean –4.03, SD 15.8 vs mean –0.77, SD 11.60 respectively) indicating average level in IG and high level in CG. The difference in the change was not statistically significant between the groups.

Side effects

To find out if empowering education is associated with prevalence and intensity of the side effects the self-monitoring diaries were analysed. The self-monitoring diary was returned by 51.2 % (n = 23) of the participants in IG and 48.8 % (n = 19) in CG. The majority had 7–13 side effects, most commonly fatigue, cold sensitivity, and nausea. Most of the participants experienced moderate to severe side effects during the first CTX cycle. When exploring the number and severity of side effects during cycles 1–4, there was a statistically non-significant difference between the groups; however, severe diarrhoea occurred more frequently in CG compared to IG.

Morbidity

To find out if empowering education is associated with morbidity, the contacts to outpatient clinic were monitored. During the cycles 1–4 IG had four and CG three emergency room visits related to NIS, mostly due to diarrhoea and vomiting. This indicates that the intervention had no beneficial effect on emergency room visits. However, the number of contacts to outpatient clinic (Figure 13) was significantly lower in IG (median 0.00, IQR 0.00) compared to CG (median 1.00, IQR 2.00, $p < 0.001$).

Patient related treatment changes

To find out if empowering education is associated to compliance with the treatment schedule the cancellations and transfers of appointments were monitored during the research period. There was no statistically significant difference between the groups with respect to uncancelled or transferred outpatient clinic appointments.

Associations between outcome variables and demographic and clinical factors

Only statistically significant associations between demographic and clinical factors related to changes in activation level, risk of malnutrition, and QoL are described in this chapter at whole data level (Appendices 6–8). In knowledge level no statistic change was shown.

- The change in activation level was statistically significant among male compared to female participants (mean difference –4.86, 95% confidence interval –9.4 to –0.32, $p = 0.036$) (Appendix 7).
- The risk of malnutrition was associated with living conditions. Although participants of this study were not at risk of malnutrition (NRS2002 ≤ 3), risk of malmutriton desreased statistically significantly among those living with family compared to those living alone (median –1.00, IQR 1.00 vs median 0.00, IQR 0.00, $p = 0.003$) (Appendix 8).
- In QoL, social well-being was associated with living, working and morbidity. Social well-being was significantly higher in those living alone compared to those living with family (median 2.00, IQR 3.00 vs median –1.00, IQR 2.00, $p < 0.001$) and in those living with another person compared to those living with family (median 0.33, IQR 4.50 vs median –1.00, IQR 2.00, $p = 0.007$). The change in social well-being was statistically significant in those who were not at work compared to those who worked (median 1.17, IQR 5.50 *vs* median 0.00, IQR 2.54, $p = 0.025$) and in those who had no emergency room visits related to NIS compared to those who did (median 1.00, IQR 4.50 *vs* median –1.00, IQR 1.75, $p = 0.010$) (Appendix 9).

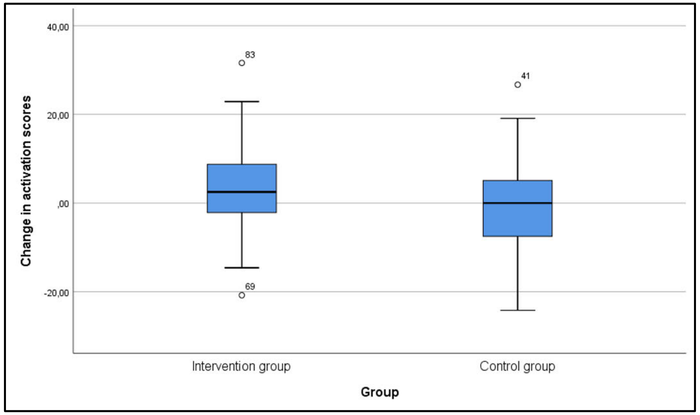


Figure 10. Change in patient activation scores in IG and CG (p = 0.060).

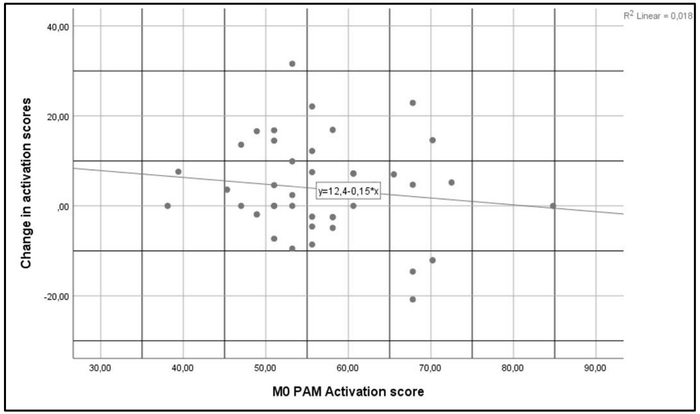


Figure 11. Change in patient activation scores within IG.

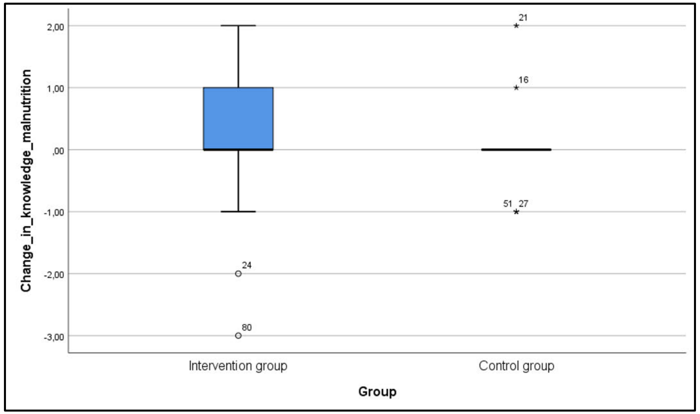


Figure 12. Change in malnutrition knowledge level (p = 0.028).

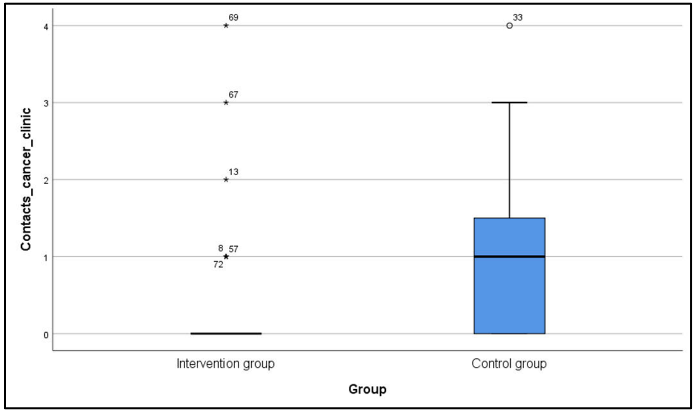


Figure 13. Number of contacts to outpatient clinic.

5.4 Summary of the main results

In this chapter, the main results of the study presented (Figure 14). They include findings of the overview of systematic reviews of nursing interventions and their effectiveness among patients with cancer. Furthermore, patients' expectations for nursing during CTX and the effect of empowering education in patients with CRC are presented.

I Theoretical phase (2017–2018)

Effectiveness of nursing interventions among patients with cancer - overview of systematic reviews (Paper I)

Nursing interventions were educational, psychosocial, psychological, activity based and interventions supporting patients' coping. The effect of educational interventions was inconsistent on QoL and attitudes, but positive on knowledge level, symptoms, and sleep. The effect of psychosocial interventions was significant on spiritual well-being, meaning of life, fatigue, and sleep. The effect of psychological interventions was positive on cancer-related fatigue. The effect of interventions supporting patients' coping was significant on psychological symptoms, fatigue, sleep, dyspnoea and functional ability. Activity-based interventions were beneficial on cancer-related fatigue.

Expectations of patients with colorectal cancer towards nursing care – a thematic analysis (Paper II)

The patients with colorectal cancer expected to be empowered with knowledge, being humanely encountered, and being skilfully cared for during the chemotherapy.

II Intervention phase (2018–2021)

Empowering patient education among patients with colorectal cancer – a research protocol for a randomised trial (Paper III)

An empowering patient education with teach-back was applied in a single-centre trial in two parallel groups with stratified randomisation according to spread of the disease and the presence of stoma (N=40+40).

The effect of empowering patient education on nutrition impact side effects in patients with colorectal cancer undergoing chemotherapy: A randomised controlled trial (Paper IV manuscript)

The difference in change in knowledge level related to malnutrition was statistically significant in the IG compared to CG (median 0.0, IQR 1.00 vs median 0.0, IQR 00, $p = 0.028$). Number of contacts to outpatient clinic was significantly lower in IG (median 0.00, interquartile range 0.00) compared to CG (median 1.00, IQR 2.00, $p < 0.001$). The difference in change in activation level was statistically nearly significant favoring the IG (mean difference 4.45, 95% CI–0.19 to 9.09, $p = 0.060$). No statistically significant change was seen in risk of malnutrition between the groups (median difference 0.00, 95% CI 0.00 to 1.00, $p = 0.33$) and QoL (mean difference–3.26, 95% CI–9.7 to 3.2, $p = 0.319$).

Empowering patient education can enhance activation level and knowledge level in patients with colorectal cancer during chemotherapy and reduce contacts to outpatient clinic, and thus reduce health care costs.

Figure 14. Summary of the main results of the study.

6 Discussion

In this chapter the main findings of the overview of systematic reviews, patients' interviews and intervention study are discussed. The limitations of the study are also considered. In the end, implications for nursing practice and recommendations for future research are presented based on the research findings.

6.1 Discussion of the results

The aim of the study was to produce new knowledge of the effect of empowering patient education in patients with colorectal cancer. Purpose was to

1) provide an overview of nursing interventions and their effectiveness in patients with cancer and use findings in planning the method and content of the intervention,
2) describe the expectations of patients with CRC towards nursing care, and use findings in planning the content of the intervention, and
3) develop and test the effectiveness of an empowering patient education on patient-reported outcomes and register data in patients with CRC.

In the following chapters the main findings of the study are discussed according to the research questions. First, findings of the overview of systematic reviews are discussed. Next, thematic analysis of patients' interviews related to their expectations for nursing are discussed. Finally, the findings of the intervention study which tested the effect of empowering patient education in patients with CRC are discussed.

6.1.1 Effectiveness of nursing interventions in patients with cancer

In the overview of systematic reviews, the research questions were related to nursing interventions and their effectiveness in the context of cancer nursing. The interventions were categorised as educational, psychosocial, psychological, activity-based and interventions supporting patients' coping. In this study, educational nursing interventions and interventions supporting patients' coping were used in intervention development. In this chapter, all five categories are discussed.

The effect of educational nursing interventions on QoL and the intensity of symptoms were conflicting and varied widely at individual level, probably due to variations in intervention delivery (mode, length, duration) as well as heterogeneity of the participants (Cook et al. 2014, Oh et al. 2016). Inclusion criteria in the reviews were, for example, the type of cancer or concurrent health problems, such as depression (Rodin et al 2007) and cancer-related pain (Zhou et al 2015). Another possible interpretation for the variation in results is that QoL may be influenced by several factors and is therefore unlikely a direct result of nursing interventions. Only few reviews reported the effect of educational interventions on knowledge level in patients with cancer, although information is an essential component in patient education. A review of preoperative education demonstrated improvements in knowledge level when using several methods such as verbal, written, and audio-visual methods (Kim et al. 2021). The timing of the intervention may explain its success as participants did not yet face CTX-related side effects on cognitive functions such as concentration and short-term memory (Dutta 2011). In some studies, the level of pain knowledge improved after the intervention, although the effect on pain relief was conflicting (Zhou et al. 2015). This may indicate that the improvement in knowledge level does not necessary lead to better self-care. Thus, it is important to study further the effect of education on empowerment in self-care actions. As mentioned earlier, educational interventions were more effective when they consisted of several components, such as information with emotional support (Hersch et al. 2009) and problem-solving with a multiprofessional approach (Zhou et al 2015). In addition, the effect improved when intervention covered all aspects of care; for instance, information, psychosocial care, practical care, and psychosexual care (Cook et al. 2014). In light of these studies, it seems that in order to be effective patient education should take into account the individual characteristics of patients using multiple methods at the same time. Also timing of the intervention is critical for its success.

Interventions supporting patients' coping were effective on both psychological and physiological symptoms in patients with cancer (Rodin et al. 2007, Rueda et al. 2011) and they also increased hope (Li et al. 2018). According to a recent study, hope can predict health-promoting behaviours, reduce perceptions of pain, and increase positive psychological changes in patients with cancer (Corn et al. 2020). Thus, it is important to study further the interventions supporting hope in patients with cancer. This overview of systematic reviews found that telephone-based interventions were beneficial for anxiety and QoL in patients with breast cancer (Cook et al. 2014, Zhang et al. 2018). This is a relevant finding as remote consultations have increased considerably since the COVID-19 pandemic.

According to latest research, both patients and healthcare providers have been satisfied with the use of e-health and were willing to continue its use (Anders et al. 2020). Furthermore, remote follow-ups have positive effects in the form of sparing patients' travel costs and time, better outcomes due to faster access to specialised care, and enhanced patient autonomy (Qaderi et al. 2020). Based on these results, the effect of telehealth in patients with cancer in different phases of the illness trajectory deserves further study.

Psychosocial nursing interventions consisted of spiritual and existential interventions. Expressive writing relieved cancer-related symptoms and sleep disturbance (Oh & Kim 2016), which is a notable outcome. Another psychosocial intervention used virtual reality (VR), which reduced anxiety and pain during chemotherapy infusions and hospitalisation of elderly patients with advanced cancer. Authors advocate the use of VR as an adjuvant intervention for these patients (Ahmad et al. 2020). Adapting VR-based interventions to alleviate cancer-related symptoms, especially fatigue, is also supported by Zeng et al. (2019). These findings require further research of VR as non-pharmacological method to alleviate cancer-related symptoms in different contexts and outcomes during the care path.

Psychological nursing interventions were effective in cancer-related fatigue especially with group-based interventions (Jacobsen et al. 2007), which supports implementation of non-pharmacological interventions to relieve cancer-related fatigue. The effect of cognitive-behavioral stress management (CBSM) was conflicting on anxiety and depression in patients with breast cancer but beneficial on mood and benefit finding and positive affect (Tang et al. 2020). Use of CBSM is supported by a trial, in which beneficial outcomes were shown on stress, QoL, social functioning and mental health but not on anxiety and depression in patients with cancer (Børøsund et al. 2020). These results require further research to find a patient group that would benefit the most from these stress-management interventions. Implementation of psychological methods is worth investing in because of the benefits to patients.

Activity-based nursing interventions had beneficial effects on cancer-related fatigue (Jacobsen et al 2007). This is in line with recent study which assessed the effect of walking on cancer-related fatigue and found beneficial effects especially when intervention time was over six weeks (Wang et al. 2022). Activity-based interventions have also affected positively on patient empowerment and muscle strength in patients with lung cancer (Rueda et al. 2011). These results are in line with the review which found a beneficial effect of individual physical activity on fatigue and physical function in patients with cancer (Abdin et al. 2019). Based on these results, physical activity should be encouraged among patients with cancer.

The nursing interventions included in the reviews were often incompletely described; their systematic analysis was thus not possible. Furthermore, it was impossible to draw conclusions as to which part of the intervention was the most beneficial. It is also important to report which professional delivered the intervention to draw conclusions about its usability in nursing practice. This updated overview of systematic reviews suggests that nursing interventions are described in more detail today than five years ago, which will help in implementation and testing promising interventions in clinical context. Based on the overview of systematic reviews, a multicomponent intervention including education as well as support for empowerment in self-care was included in the planning of the method and content of the intervention in this study. (Paper I.)

6.1.2 Expectations of patients with colorectal cancer towards nursing

In the interview study, the research question focused comprehensively on patients' expectations for nursing during CTX. Thematic analysis showed that expectations of patients with CRC related to 1) being empowered with knowledge, 2) being humanely encountered, and 3) being skilfully cared for.

Related to expectations for empowering knowledge, patients expected to have knowledge to take care of themselves at home between the CTX cycles which has also been evidenced in previous research (Rasmusson et al. 2013, Weert et al. 2013, Tomball et al. 2014, Vaartio-Rajalin et al. 2015, Simacek et al 2007). Knowledge expectations were also related to NIS and their self-care. Participants expected to have individually targeted information about the nature of side effects, which confirms previous research of expectations of being offered tailored knowledge in different phases of the care path (Beaver et al. 2010, Vaartio-Rajalin et al. 2014). Some of the patients perceived it important to be aware of the care process and related decisions. This is in conflict with previous research findings of leaving care decisions to health care professionals (Almyroudi et al. 2011, Tombal et al. 2013) reflecting perhaps some differences in culture and legislation between countries in health-related decision-making. The received knowledge has not always corresponded to patients' expectations (Klemetti et al. 2015) and threfore patients' education needs to be tailored at individual level in order to be effective.

Related to expectations of human encounter patients expressed the desirable characteristics of the nurse and patient-nurse interaction. Patients felt they were encountered humanely when the interaction was compassionate, honest, and supported hope. This is in line with previous research in patients with advanced cancer (Thorne et al. 2014). It is important for nurses to engage in this type of interaction from early on in their careers and maintain the skills that reflect a good quality nursing care (McGormack & McCance 2017). Factors that are associated to patients' feeling that they have been encountered humanely need to be further examined. In this study, patients perceived the psychological support sufficient through the nurse-patient relationship. This supports earlier research related to psychological support in patients with cancer (Merckaert et al. 2010, Baker-Glenn et al. 2011, Dubruille et al. 2015, Tondorf et al. 2020.) A study of patients' intentions regarding the use and uptake of psychological support revealed a vulnerable patient group with high levels of distress but low intention to use these services. The authors suggested discussing patients' expectations related to supportive care during routine hospital visits. (Tondorf et al. 2020.) Spiritual needs are common among patients with cancer, yet they seem to be seldom asked about (Astrow et al. 2018). In order to meet these expectations, sufficient human resources should be allocated to outpatient clinics.

Related to expectation of being skillfully cared for, the systematic assessment of care was emphasised. This expectation should be taken into account in care plans. CTX may last from three to six months, and even longer in advanced cancer; patients' expectations may thus change during the care (Ryhänen et al. 2012, Thorne et al. 2014). Furthermore, the expectation of trust was expressed as a confidence in the professional skills of the nurse. In previous literature, professional competence of a nurse is seen as a prerequisite for person-centred care (McGormack & McCance 2017). Expectation of advocacy emerged in presenting patients' care needs to other health care professionals. This supports previous study (Vaartio-Rajalin & Leino-Kilpi 2011) of nurses responding to the ethical and clinical needs of the patient by acting as a mediating third party. This task is particularly highlighted during CTX, when doctors meet patients less often than nurses.

Based on the findings of the interviews, the educational intervention in this study was based on empowering knowledge. Patients were humanely encountered by using active listening and encouraging them to share their experiences of self-care. Patients' views and self-determination were respected. In addition, patient-reported data was used by tailoring the content of the education according to the patients' existing knowledge and activation level (Appendix 2). The characteristics of the patients were taken into account by offering knowledge at the individual level and by confirming patients' understanding by using the teach-back method. The expectation of being skilfully cared for was confirmed by recruiting a research nurse with extensive work experience of oncology to deliver the intervention.

6.1.3 Effectiveness of empowering education in patients with colorectal cancer

The third research question focused on developing and implementing an empowering education using teach-back in the clinical context and its testing on activation level, knowledge level, risk of malnutrition and QoL in patients with CRC during CTX. The hypotheses of the intervention study were that patients with CRC who participate in nurse-led empowering education of NIS and their self-care vs. standard education have better activation level, knowledge level (primary outcomes), lower risk of malnutrition and higher QoL (secondary outcomes) after a 2-month follow-up period. In addition, the effect of empowering patient education was assessed by monitoring side effects' prevalence and intensity, morbidity, and patient related treatment changes (register data).

The intervention development was a systematic process in co-operation with clinical staff and patient experts by experience. Empowerment was supported by tailoring the education based on patients' baseline activation level, expectations for additional knowledge and experiences of self-care of NIS after the first CTX. In addition, teach-back was applied to enhance the tailoring of the knowledge (Figure 5). According to the results, the effect of the intervention was 1) beneficial on patient activation scores in the IG, 2) statistically significant in malnutrition related knowledge in the IG, and 3) statistically significant in the number of contacts to cancer clinic in the IG. The reason for the minor effect might have been contextual, indicating that the patient education was already empowering in this particular context, and the intervention may not have been sufficiently different from the standard education in the outpatient clinic.

Activation level

There was a positive trend in the change in activation scores in IG which in line with previous research (Hibbard et al. 2009, Howell et al. 2023). The finding may suggest that empowering education has the potential to increase patients' awareness of having an important role in self-care (Fumagalli et al. 2015). Therefore, this kind of brief intervention warrants further research. In this study, existing up-to-date material of the cancer clinic was used for patient education. In case the material was lacking knowledge from previous research was used. However, it may be assumed that participants with higher activation scores might have benefited from additional new research knowledge to further develop their self-care skills (Appendix 2). Throughout the dataset, activation scores increased more in men than women. This may be explained with previous studies suggesting that women seek knowledge from different sources more actively than men, who might benefit more from information tailored to them (Bidmon & Terlutter 2015).

Knowledge level

The change in knowledge level was higher in IG related to malnutrition. This may be because patients are offered a lot of information on the side effects, whereas education on the risk of malnutrition and its prevention may not be a routine in the outpatient clinic. The knowledge level as a whole did not improve in contrast to some other studies (Siekkinen et al. 2015, Zhou et al. 2015, Kesänen et al. 2016, Kim et al. 2021). Earlier, longer intervention times have produced higher knowledge levels (Zhou et al. 2015) which might have been the case in this study, too. It must be noted that the knowledge level was already high at baseline. Moreover, patient education covered only the side effects that patients had experienced after the first CTX, which may have contributed to the results of the knowledge test.

Risk of malnutrition

The risk of malnutrition was not prevalent among the participants, which may have been related to the timing of the intervention, i.e., 6–8 weeks after surgery. The earlier evidence supports that particularly, patients at risk of malnutrition benefit from nutritional interventions (Kondrup et al. 2003); however, being at risk was not an inclusion criterion in this study for it was assumed that risk of malnutrition is common in patients with CRC. Only few studies have assessed the effect of educational interventions on nutrition-related outcomes such as body weight, energy and protein intake, BMI, and everyday life function (Park et al. 2012, Lin et al. 2017, Xie et al. 2017, Cate et al. 2020) in patients with cancer, and findings have been conflicting (Paper I). In this study, the risk of malnutrition scores decreased after the intervention among those who lived with family. This may indicate that help is provided by family members in situations where patients are unable to source or prepare food themselves; due to fatigue or nausea, for instance.

Quality of life

The change in QoL was negative in both groups, which is in line with previous studies (Zhou et al. 2015, Hersch et al. 2009). After the intervention there was no improvement in QoL in both IG and CG being in accordance with previous studies (Tong et al. 2009, Goździewicz et al. 2017, Son et al. 2018, Xu et al. 2019, Salvetti et al. 2021, Oh et al. 2022). As QoL consists of many different dimensions, such as physical, social, emotional, and functional well-being (Cella et al. 1993) it is unclear whether the change was due to the intervention, chemotherapy, or the disease itself, as discussed in previous studies (Cook et al. 2014). Earlier the prevalence of NIS has been associated with poorer QoL (Tong et al. 2009, Hoffman 2013, Karabulut et al. 2021) which might have contributed to the deterioration of QoL in this study as well. These findings may also indicate that it takes a longer period to detect improvements in QoL. It is also said that “ignorance is bliss”. In oncology context, some patients do not necessarily want detailed information but rather avoid awareness of bad news (Almyroidi et al. 2011) which may affect negatively on QoL.

Number and severity of side effects

The number and severity of side effects did not differ between the groups. This result is in line with some earlier studies (Paper I), but conflicts with some others (Coolbrandt et al. 2018). Furthermore, previous research has found improvements in association of empowering education with cancer related pain intensity (Collette et al. 2018). In this study, severe diarrhoea occurred more frequently in CG compared to IG. Related to morbidity, participants in the IG had fewer additional contacts with health care compared to the CG. This might suggest that the intervention enhanced self-care skills, and thus, reduced the need to contact health care professionals. During cycles 1–4, participants in IG had three and in CG four emergency room visits, which resulted more often in hospitalisation in CG. The result may support earlier research of higher activation scores being associated with reduced hospitalisation and emergency room visits. (Hibbard et al. 2009, Greene & Hibbard 2011). The systematic review of Ream et al. (2020) supports telephone-delivered educational interventions for patients with cancer to reduce symptom severity and enhance self-care (Ream et al. 2020). Based on these results, ongoing monitoring and self-care of the side effects is needed through out the care. Attention should be given to those patients who have multiple side effects, and their self-care methods should be supported to avoid deterioration of nutrition intake, and thus, of quality of life.

Visits to ER, additional contacts to outpatient clinic and patient related changes in treatment schedule

After the intervention, there were fewer additional contacts to outpatient clinic in IG compared to CG. The outcome is in line with earlier research according to which increased activation has been associated with a positive change in self-care (Hibbard et al. 2007). Improvements in activation level have also reduced hospital and ER visits, thereby reduced healthcare costs (Greene & Hibbard 2011). In this study, no differences were found between IG and CG related to ER visits and patient related changes in treatment schedule.

In conclusion, the intervention study showed that empowering patient education seems to be beneficial for the knowledge level of patients with cancer. It can also increase activation level and decrease the number of contacts with health care. Therefore, it can save on the costs of health care. These results justify adopting empowering education as part of routine care among patients with CRC during chemotherapy. Saving costs related to reduction in the number of contacts with the outpatient clinic calls for further research.

6.2 Validity and reliability of the study

In this chapter, validity and reliability of the study are discussed. In the overview of systematic reviews, validity is discussed from the methodological point of view. In qualitative interviews, trustworthiness of the study is discussed. In the intervention study, validity refers to the extent to which the measurement may or may not directly measure the desired characteristic. In this study, statistical conclusion validity, internal validity, external validity, and construct validity of the intervention are discussed (Polit & Beck 2021). Reliability refers to the extent to which the measurement is reproducible, i.e., the ability to provide the same value under the same conditions (Lachin 2004).

6.2.1 Validity and reliability of the overview of systematic reviews

The literature search strategy for both the original and updated overview of systematic reviews was documented (Paper I, Summary Appendix 1) to support its scientific validity (JBI 2014). To increase the validity in data collection, pre-defined research questions and the PICOS phrase were used. The inclusion and exclusion criteria of references were adhered to throughout the process. The literature search was conducted in four scientific databases. Because only studies in English language were accepted, there may be a risk that all relevant reviews were not included in the review. By including only quantitative systematic reviews patients' experience of the effectiveness of interventions may have excluded. However, the original studies mostly applied patient-reported outcomes. The time frame for publications was set to ten years, but the time frame of the original studies in the systematic reviews varied from no restrictions up to the beginning of 1990s (JBI 2014).

The overview of systematic reviews was conducted following the Methodology for JBI Umbrella Reviews (JBI 2014) and reported according to the PRISMA guidelines, which enhanced reliability. Furthermore, the literature search was confirmed by an information specialist. The selection of studies and assessment of the methodological quality was performed by two independent researchers (MS, LT). Only interventions delivered by nurses were accepted to reduce the risk of reporting bias. However, due to lack of reporting, it was not always possible to verify this. Reviews of at least medium methodological quality were approved. In addition, an extraction sheet was developed (Appendix 3) to collect the data systematically from the included reviews (JBI 2014).

In the analysis, the classification of interventions was difficult due to the complex nature of the nursing interventions; thus, the categories were partially overlapping. Nursing interventions may also comprise forms of psychological and social support. Similarly, supportive interventions may also consist of educational components. To support the validity of the categories they were verified by two researchers (LT, MS). A strength of the updated overview of systematic reviews is that several e-health interventions were included; in the original overview of systematic reviews, they comprised the minority.

6.2.2 Trustworthiness of the interview study

In the interview study, the theoretical approach was patient-centredness and patients' experiences were the focus of interest. These premises guided the research method as well as the research questions and development of the interview guide. Next, criteria suggested by Lincoln and Cuba (1985) are applied to consider the trustworthiness of the study.

Credibility

Credibility, i.e., confidence in the truth of the data and its interpretations (Polit & Beck 2021) was increased by reflexivity which is essential to assess trustworthiness (Dodgson 2019). Reflexivity means sensitivity of the researcher's influence on research at all stages of the study (Koivunen 2017). It is argued that in qualitative research, the researcher is the principal research instrument. If participants do not consider the researcher trustworthy, the validity of the results is questionable. (Adler 2022.) To improve credibility, the researcher explained to the participants her position as a postgraduate student, the reasons for conducting the research as well as her connections to the organisation (Paper II). The fact that the researcher is an outsider and not one of the clinical staff may enhance the trust between participants and researcher. However, researchers' own perceptions and biases may prevent them from being completely objective (Adler 2022). Credibility was supported by recruiting participants with experience of being affected with CRC and undergoing chemotherapy (Granaheim et al. 2017). The interview guide was prepared based on a previous study of patients' expectations by Vaartio-Rajalin et al. (2015). Furthermore, a comprehensive literature search was made only after the thematic analysis to minimise the influence of the researcher's existing knowledge on the data collection and analysis. The interviews lasted quite a short time (mean 42 minutes), but rich data was obtained during these discussions. The analysis was carried out in accordance with the thematic analysis guidelines by Braun & Clarke (2006), which supported its credibility. Analysis was conducted at semantic level, identifying the themes within the explicit meanings of the data, and refraining from interpretation to make sure that the results corresponded with the experiences of the participants (Braun & Clarke 2006).

Dependability

Dependability, i.e., stability of data over time, was enhanced by using the interview guide (Polit & Beck 2021) and by conducting the data collection over a short period, 20th October – 27th November 2017. Data was collected to the point where saturation was reached, which means that a sense of closure was attained because the data did not produce any new information (Polit & Beck 2021). Therefore, the sample size (n = 15) was considered sufficient. In this study, nurses recruited the participants, which may pose a risk of selection bias. However, the clear inclusion criteria guided the recruitment through out the study.

Transferability

Transferability, i.e., the extent to which findings are transferable to another environment (Polit & Beck 2021) was confirmed by describing the characteristic of participants and settings so that the readers are able to make assumptions of transferability of the findings in their own clinical context. In the end, the decision of applying the intervention in own context is addressed to the readers (Paper II) (Granaheim & Lundman, 2004).

Confirmability

Confirmability, ie., objectivity about the accuracy of the data, was confirmed by assuring that the dataset represented data generated by patients (Polit & Beck 2021) by constantly asking research question from the data during the analysis to separate patients' actual expectations from general experiences. The quotations (Paper II) confirm that the themes emerged from the patients' experiences and not those of the researcher (Sutton & Austin 2015). Furthermore, confirmability refers to objectivity when there is consensus between at least two independent researchers about the correctness and relevance of data (Polit & Beck 2021). In this study, investigator triangulation supported confirmability as supervisors (HL-K, RM) cross-checked the themes formulated by the researcher (LT) and a consensus on the themes was reached by all authors (Elo & Kyngäs 2008, Polit & Beck 2021). Visual representation of data gives readers an idea of how the researchers came to their findings (Figure 6) and makes the research process more transparent, and thus trustworthy (Adler 2022).

6.2.3 Validity and reliability of the intervention study

In this chapter, the validity and reliability of the intervention study is examined from four perspectives: statistical conclusion validity, internal validity, external validity, and construct validity (Polit & Beck 2021).

Statistical conclusion validity

Statistical conclusion validity i.e., the extent to which correct conclusions can be made of the relationships between the variables (Polit & Beck 2021), was supported by conducting appropriate statistical tests under the supervision of a biostatistician. According to a power analysis the sample of 40 + 40 was considered large enough by assuming that 7 points' difference in patient activation scores might be reasonable to detect a difference in outcomes. The intervention failed to show statistical difference in outcomes between the groups, which may suggest that the intervention might not have been powerful enough to maximise the effect or different enough from the standard education in this context.

The loss of participants may pose a problem for the power of the trial biasing the outcome in the direction of no effect (Dunbar-Jacob 2012), alter the generalisability of the findings (Polit & Beck 2021) and cause a significant threat to the statistical validity of intervention studies (Szalacha 2012). In this study, the loss of participants was covered by continuing the recruitment until the sample size was reached (40 + 43). The inclusion criteria were broad in order to enhance successful recruitment. Retention means maintaining contact with participants to encourage them to continue to participate throughout the study (Gul & Ali 2009). In this study, attrition rate in IG and CG was 33.85% and 36.50%, respectively. This might have affected by COVID-19 pandemic and changes in participants life situation and care. Participation was encouraged by contacting the eligible participants by phone, which offered individual attention and an opportunity to build trust between participants and the researcher. During the trial, procedures were simplified to reach the potential participants more effectively. Effective, sustained communication with the research team by phone and extra visits to the outpatient clinic were arranged when deemed necessary.

The outcome data of those enrolled and randomised to the IG and CG were accounted for in the primary analysis. The questionnaires of those who did not complete both measurements (M0, M1) were left out of the study. The participants were randomised to IG and CGs according to the spread of the disease and existence of stoma, and the differences in demographic and clinical characteristics of participants were statistically non-significant at baseline. Therefore, the differences in outcomes between the groups can, in principle, be atributed to the causal effect of the intervention (Szalacha 2012).

Internal validity

Internal validity, i.e., the extent to which a causal relationship between the variables can be determined and the strength of the evidence that the intervention caused the outcome (Polit & Beck 2021). In this study, subgroup analyses between clinical and demographic factors and outcomes were made to specify for whom the intervention works best. A limitation is the small number of observations in the subgroups. The potential for significant findings by chance may increase because of multiple comparisons; therefore, the results should be interpreted cautiously. (Szalacha 2012.) Blinding of treatment assignments to the patients and clinical staff (Lachin 2004) was not possible in this study because the participants and clinical staff were reminded of the intervention after the second CTX.

Reliability of the instrument refers to the ability to consistently measure an attribute (Szalacha 2012). In this study, both general and cancer-specific patient reported-outcome measures (PROMs) were used, which means that the responses come directly from the patient, without the researcher's interpretation (CIHI 2015). Exception of this was the NRS2002 measurement. If participants had assessed that surgery still posed a risk of malnutrition, the researcher interpreted the answers as opposite. This was based on consultation with a clinical nutritionist, oncologist, and literature (Aoyoma 2020). The surgery no longer posed a risk of malnutrition as CTX starts after 4–8 weeks after surgery (Schmoll et al. 2012). It is also notable that at the time of recruitment, the majority of the participants were not at risk of malnutrition, which limited the ability of the study to detect the effect of the intervention on this outcome (Kondrup et al. 2003). To increase validity, the RasOma and the self-monitoring diary were assessed by two patient experts by experience. In addition, the content of the RasOma was confirmed by a research group consisting of a clinical nutritionist, two nurses, an oncologist, and the researcher.

Reliability of the intervention delivery was supported by training the research nurse. Furthermore, the research nurse reported the length and content of the intervention after each education session. The study setting was controlled by conducting the sessions in a private room without external distractions. In the absence of the research nurse the researcher conducted the intervention. A change of interventionist could have made the experience different for the participants thus compromising the internal validity. It was discussed in the research group whether the characteristics of the interventionist could have a significant impact on the outcome. (Dunbar-Jacob 2012.) Unplanned event, COVID-19, led to changes in the protocol in 2020. First, the third (M2) measurement was omitted from the protocol due to prolonged recruitment. Second, the Ethics Committee approved a telephone survey to be used instead of a postal survey, if necessary. Third, at the start of virtual visits, the intervention was postponed by one week in connection with the second CTX. Finally, due to the COVID-19 pandemic restrictions in Cancer Clinic, recruitment was paused for six months in 2020. When recruitment started again, the content and method of the intervention were reviewed with the research nurse. These protocol changes were minor and, to the researchers' understanding, did not affect outcomes.

External validity

External validity, i.e., generalisability of the results across people, settings, and time (Polit & Beck 2021). Based on the clinical and demographical characteristics the participants represented well the population, which enhances the generalisability of the results. The participants were recruited during 31 October 2019–31 December 2021 in one University Hospital Cancer Center, Outpatient Clinic, which may have posed a risk of exposing the elements of the intervention to participants in the CG, thus diluting the effect of the intervention. However, mutual interaction was limited as patients with CRC were not systematically placed in the same room during the patient visits.

Construct validity

Construct validity, i.e., the degree to which an intervention is a good representation of the underlying construct and whether it is adequately captured (Polit & Beck 2021). In this study, education was based on the theory of empowerment. Construct validity was supported by reporting the development process of the intervention, its content and construct and by publishing a detailed study protocol. The intervention was developed using intervention mapping approach (Kok 2014) and intervention research literature (Melnyk & Morrison-Beedy 2012). In addition, feasibility of the intervention was discussed in a multidisciplinary research group. A small-scale study to test the proposed study design might have been useful prior to the trial to find out how well the processes fit together, e.g., willingness of nurses and doctors to contribute to the research, commitment to the protocol, time and resources for recruitment, intervention delivery, retention, and follow-up (Giangregrorio & Thabane 2015). At the beginning of the recruitment, some issues related to the clinical context were resolved. Reinforcement sessions during the follow-up might have strengthened the intervention effect. On the other hand, implementing these additional sessions into a clinical context could be challenging due scarce resources and may be found burdensome by patients. The patients with higher activation levels were not offered information different from other educational materials, which could have helped them to develop their self-care skills further.

6.3 Implications for nursing practice

Nursing interventions and their effectiveness among patients with cancer

The overview of systematic reviews showed that the role of a nurse in cancer care is comprehensive: teacher, consultant, and supporter. Nursing interventions in patients with cancer have positive effects on several patient-related outcomes. Interventions that include multiple elements such as knowledge and emotional support are the most effective. To improve the effectiveness of the intervention individual characteristics of the participants should be considered; for example, educational level, disease stage and treatment trajectory. The overview of systematic reviews showed that a supportive and empathetic relationship between the patient and a nurse appears to strengthen the intervention’s effect. Therefore, it is important for nurse leaders to support this relationship by paying attention to the nursing resources and the way work is organised in outpatient clinic.

Patients’ expectations for nursing during chemotherapy

Patients’ expectations were related to empowering knowledge, human encounter, and skillfull care. These expectations are concrete and can easily be implemented in nursing practice to enhance patient-centred and evidence-based nursing. Asking patients’ expectations for care during the care path helps to tailor information and enhance patient-centredness. Human encounter such as compassion, honesty, and the maintenance of hope develop through work experience, but it is important to practice these skills during nursing studies and to maintain them at work through continuing education. This kind of behaviour can support patients to become empowered in self-care.

Empowering patient education in clinical context

In the intervention study, the majority of the participants (83.3%) experienced moderate to severe nutrition impact side effects during the first cycle of chemotherapy, and more than half of the participants experienced them during the second and third cycle. Therefore, an individual and documented care plan with systematic assessment could help to set and achieve the goals of side effects’ self-care. As findings showed that activation level in men improved after the intervention, action needs to be taken to encourage men to be active in their self-care.

Applying a brief intervention of empowering patient education in the care of patients with CRC improved the knowledge level. Therefore, its implementation in the care of patients with cancer is encouraged. The intervention study showed that patient-centred approach that takes into account patients’ activation level in patient education may improve activation, which is related to individuals’ knowledge, skills, and confidence to manage their own health. The measurement of patient activation level can be applied in both tailoring patient education and assessing the outcomes. At present study, the empowering education reduced patients’ additional contacts to outpatient clinic which may reduce health care costs. Therefore, applying empowering education in the care of patients with cancer is recommended.

6.4 Recommendations for future research

Nursing interventions and their effectiveness among patients with cancer

The overview of systematic reviews showed that educational interventions were the most effective when different elements were combined together, such as knowledge and emotional support. If using only one element, for example video or information alone, the intervention may not be effective. These multicomponent interventions should be further tested by including, for example, patient organisations and a multidisciplinary approach. In this study, the intervention was rather challenging for patients and nurses. Therefore, it would be useful to develop and test further brief educational interventions and analyse their effectiveness. It is important to also include digital solutions for patients who can use them. In intervention research, it is important to report the development and underlying theory of the intervention to provide reliable guidelines in clinical practice. This information also helps nurses and nurse leaders to select the most appropriate interventions in patients' care. In intervention research, recruitment can be challenging. Acceptability of intervention among those whom it is intended or who will deliver it is crucial to success. Acceptability may be improved by involving patients in intervention planning (Richards 2015).

Patients' expectations for nursing during chemotherapy

In this study, statistical methods were used to measure the effectiveness of the intervention. In order to be fully aware of the effect of empowering patient education, patients' experiences should also be studied by using qualitative methods. As previous literature has shown, patients' expectations may vary during the care path (Thorne et al. 2014) and be influenced by personal, situational, and clinical factors (Vaartio-Rajalin et al. 2014, 2015) Therefore, it is necessary to identify whether there are certain groups of patients who would benefit in particular from these brief interventions.

Empowering patient education in clinical context

Patient activation level showed improvements among patients who participated in empowering education. There is a shortage of research analysing the meaning of patient's activation level in education. This would be an important adding in future research, especially related to empowerment of patients. Further research is needed on different methods of how family members can support their loved ones with cancer. For example, here social well-being was lower among patients who lived with family. On the other hand, scores in risk of malnutrition were lower in those who lived with family. In interventon studies, inclusion criteria of patients are important. In present study, nutriotional risk in both groups was rather low, and changes then were minor (Kondrup et al. 2003). In future studies, inclusion criteria and randomisation should be carefully defined. Attention should be paid to process evaluation i.e., the extent to which the intervention was delivered as intended and consistency with the research protocol throughout the research period, e.g., by observing or recording the implementation of the intervention. Contextual factors may also contribute to the intervention effect; therefore, it is necessary to ensure that the existing practice and the content of the intervention differ sufficiently from each other. The timing of the intervention also earns careful consideration. At present study, the intervention was delivered after the second cycle of chemotherapy. During that period, patients already had experience of nutrition impact side effects and their self-care, so the timing was considered appropriate for the education and self-assessment. As patients' expectations for their care vary during the illness, additional studies should be carried out to test the effect of empowering patient education at different stages of the care path, e.g., before and after surgery and during the follow-up as treatments are over. Finally, to perform an economic assessment in order to know the cost-effectiveness of the intervention implementation is also an important consideration for future intervention studies.

7 Conclusions

The results of this study showed that especially educational and multicomponent nursing interventions are effective in patients with cancer. Thematic analysis showed that patients' expectations for nursing during te chemotherapy focused on empowering knowledge, human encounter, and skilfull nursing care. This study showed that empowering education with teach-back improves knowledge level related to malnutrition and reduces contacts to the outpatient clinic in patients with colorectal cancer. It may also enhance activation level, which is closely related to empowerment. The results of this study suggest that empowering education has the potential to improve the self-care of patients with colorectal cancer when measured as additional contacts to health care. However, these results need further research. It is also important to recognise those patient groups that may especially benefit from brief nursing interventions of this kind.

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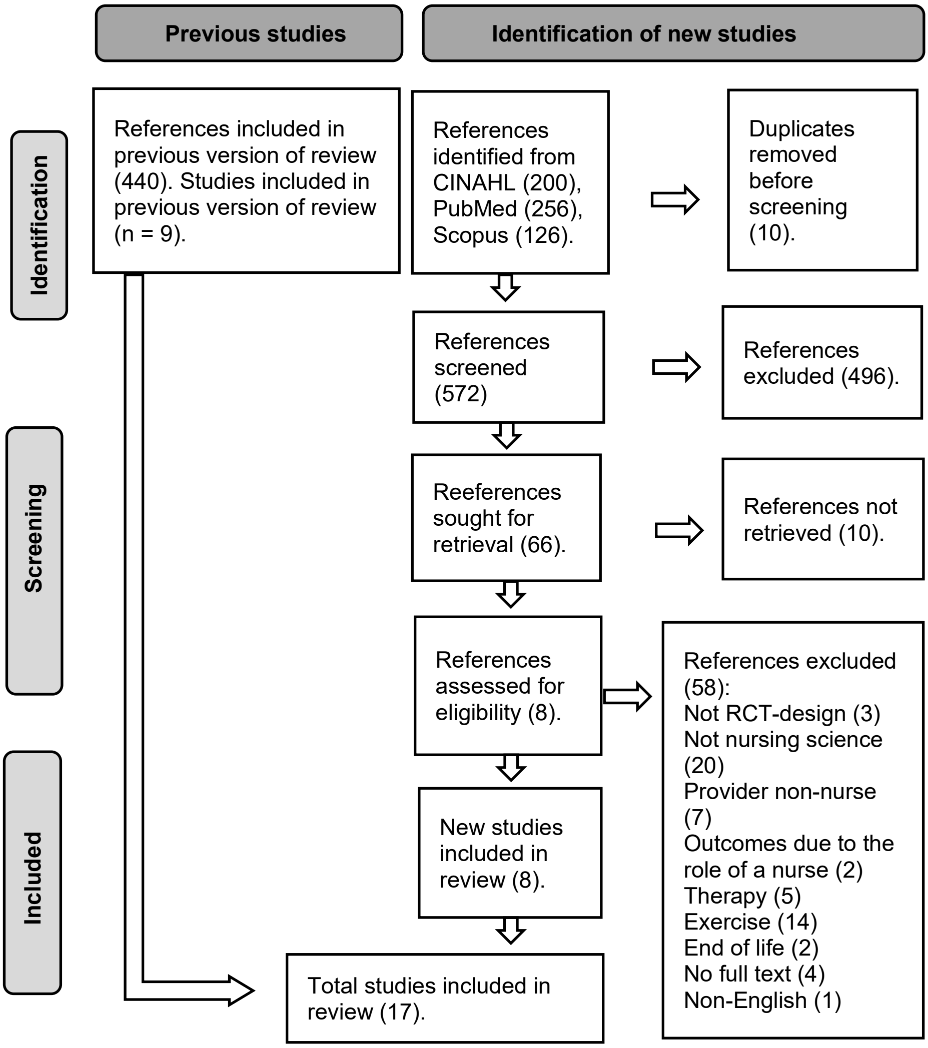
Appendices

Appendix 1. PRISMA flow diagram for systematic reviews (Modified from Page et al. 2021).



Appendix 2. Tailoring education to patient activation level (reprinted with permission from Insignia Health 2017).

Low Activation (Levels 1 and 2)

Characteristics	Implications
People feel overwhelmed of caring for own health and being involved in own health care.	Simplify information and help the individual focus on one goal and related action step(s) that they can be successful with and begin to build the confidence.
Individuals may struggle to set realistic and achievable goals. They focus on day-to-day coping rather than on specific goals achieved over time.	Focus on a specific task, e.g., taking weigh every day and keeping a written record. Make sure that the task is achievable.
Can experience both positive and negative emotions daily, making it difficult to absorb and apply new information. They are not open to doing things differently than before. They may have trouble storing new information. They may lack confidence and are accustomed to failure.	Help individuals see what they can do well, support self- confidence that they “can do,” be proud of them when they do well. Encourage in actions that are likely to success and feel positive by encouraging the development of positive emotional experiences.
Individuals may not know how to solve problems. They can easily give up when encountering problems or barriers.	Work with the individual on problem-solving. Discuss the likely obstacles that hinder the achievement of the goals and how those barriers might be overcome.
Individuals may have difficulties to understand the importance of self-care or see how own actions and health are connected. Individuals are likely to think that their providers are in charge of their health. They often see themselves as passive recipient of care rather than being equal and active partner in care with clear responsibilities of own health.	With caring and compassion, be explicit that patient is responsible for important areas of care. Help them be confident that they can take resposibility.
Knowledge gaps may be significant. Information easily overwhelms. Individuals typically will not express their lack of understanding.	Break down information into smaller components. Ask the individual to tell you how they would explain the information to a friend.
Self-care skills may be poor. May lack of confidence to engage in even simple self-care behaviours because of unsuccessful attempts to manage own health in the past. Self-care skills have not developed. Feeling overwhelmed.	Health care professionals can have a strong impact on building confidence by saying “I know you can do this.” You can start by being successful in managing one or two key self-care tasks. Individuals should take ownership of own health. Therefore, it is important to focus on goals the individuals care about, even if they are not the top clinical priorities

Higher Activation (Level 3)

Characteristics	Implications
Individuals have positive emotional balance. They do not feel overwhelmed in managing own health and healthcare. They have emotional strength to tackle challenges and develop new skills. Times of stress can set them back, though they have the ability to recover.	Ask how much stress individuals experience. If the current health situation is highly stressful, do not assume that the activation level remains all of the time.
Individuals are goal-orientated and have positive experiences setting and achieving health goals.	Individuals can handle more complicated information while working on different goals simultaneously. Goals can pursue guideline or best-practice behaviours. Individuals can still benefit from shared problem-solving, and anticipating barriers and how they can overcome them.
Individuals understand their role and may describe themselves as ‘part of their healthcare team.’ They voice concerns and questions if they do not understand information that is shared.	Individuals are full participants in their health and healthcare.
Individuals are well informed. Their knowledge is strong about health condition, responsibility, self-monitoring, and the use of medication. There may still be some knowledge gaps related to lifestyle behaviours (nutrition, physical activity, coping with stress). Individuals may want to clarify so that they are sure to get it right.	Be prepared to be knowledgeable and to believe that patients are knowledgeable. They know the importance of self-care but may be missing some clinical details or may be struggling to apply information, particularly in lifestyle areas. Give time to read and think about the information and ask questions.
Individuals have experience of successfully managing own health. Have confidence and skills for improved self-care. They are looking for information and guidance that will help them continue to manage their health by building on their current skills. They may have difficulty staying on track under high stress.	Individuals want to be more informed and knowledgeable. This supports their positive affect and will help them be more open to apply new information to improve self-care skills.

Highest activation (Level 4)

Characteristic	Implications
Individuals are consistently positive and have a strong 'can do' attitude. They are not overwhelmed with the task of managing their health and healthcare.	Individuals can tackle new challenges. They are resilient and can bounce back from changes to their routines.
Individuals have a strong goal orientation and consistent positive experiences setting and achieving health goals.	Can tighten the goals to meet or exceed guidelines. Goals may also focus on strategies to prepare for potential self-care obstacles. Lifestyle (nutrition, physical activity, coping with stress) can be the most important source of improvement.
Individuals are self-aware and understand their role in health care. They act as 'their own advocates.'	Support active involvement. Be prepared to answer the questions.
Individuals are wellinformed. The knowledge of health condition and own role in self-care is strong.	Look to recent information, including research, that might help them further develop their skills. New information can help people push beyond guidelines with lifestyle behaviours, as well to prepare for obstacles and changes to their routines. It can help maintain the high degree of motivation and focus on own health.
Individuals have consistent experience of successfully managing town health. Have confidence and skills for improved self-care. People are looking for information and guidance to continue to manage their health by building on current skills. There may be difficulties staying on track when under high stress.	Best opportunity to develop new skills is with lifestyle behaviours – nutrition, physical activity, and coping with stress. Help people plan for potential challenges for their health routines.

Appendix 3. A data extraction sheet for systematic literature reviews (modified from Paper I).

Author(s), year, country, intervention type, methodological quality (AMSTAR)	Population, number of studies (n), design	Purpose	Intervention (provider, type, format, sessions)	Comparator	Outcomes
Cook et al. 2014 **Australia** **Educational, Interventions supporting patients' coping** **AMSTAR 8 / 11**	Adults with gynecological cancer receiving medical care. RCTs (n=6) and non-randomised (n=3)	To test the efficacy of nursing interventions in quality of life, satisfaction with care and psychological outcomes	**Provider:** A specialised nurse **Type:** Specialist nurse intervention (Advanced practice nurse (APN) & Psychiatric Consultant Liaison Nurse (PCLN)) related to informational and educational (8), psychosocial (6), physical or practical (9) or psychosexual (4) needs of the participants **Format:** video, psycho-ducational programme, individual symptom education programme, idividualised pain intervention, support group, rehabilitation programme, telephone follow-up **Sessions:** 4-5 (mean).	Usual care	Quality of life (QOL): PCLN added with APN intervention improved significantly the QoL, PCLN on its own improved significantly both mental and physical scores. Involvement of a specialist nurse improved the QoL (n=4 studies). Satisfaction with the care: A telephone follow-up improved QoL, decreased uncertainty and was the most preferred mode of follow-up. Psycho-educational and individualised pain intervention were helpful. Psychological outcomes: Uncertainty improved significantly and was enhanced by the inclusion of PCLN. Non-significant effect on anxiety and depression in individual symptom education programme. A statistically significant increase in coping with nurse-led rehabilitation programme during 3–12 months in experimental group. A positive change in uncertainty, body image and coping (n=3).
Coolbrandt et al. 2014 **Belgium** **Educational** **AMSTAR 9 / 11**	Adult cancer patients with chemotherapy (outpatients)	To describe the characteristics and evaluate the effectiveness of complex	**Provider:** Clinical nurses trained to the intervention. **Type**: Patient education (n=6), symptom assessment (n=10), re-	Usual care	Cognitive-behavioral intervention: symptoms were reduced by 15–28%. A psychoeducational intervention and a telemonitoring program: significant improvements in anxiety levels.

	RCTs (n=11)	nursing interventions targeting multiple symptoms in patients receiving chemotherapy	evaluation the symptoms and modification of strategies (n=5), counseling or coaching. **Sessions**: ranging 3–10 periods over 4–5 months. Contact time 1–7 h. Number of contacts flexible and tailored to the patients' symptom experience (n=3). **Format:** Combinations of face-to-face and telephone contacts.		A complementary care intervention, a focused narrative interview and a telemonitoring program: improvement in anxiety, non-significant differences between intervention and control group. Nurses played a meaningful role in the management of anxiety with early recognition and a specific set of psychotherapeutic interventions (n=2).
Oh & Kim 2014 Korea **Psychosocial AMSTAR 8 / 11**	Adult patients with cancer RCTs (n=7) and non-RCTs (n=8) (5 reviews excluded for provider non-nurse)	To evaluate the effects of a spiritual intervention	**Provider:** RNs (n = 10), psychologists (n = 4), a dietitian (n = 1) and an oncologist (n = 1). **Type:** Religious interventions (n =10): spiritual care (n = 7), spiritual counseling (n = 1), oncologist assisted spiritual intervention (n = 1), spiritually focused meditation (n = 1). Existential interventions (n=5): meaning-centered psychotherapy (n = 2), a meaning-of-life intervention (n = 1), a meaning-making intervention (n = 1), a logo therapy-based resilience promotion program (n = 1).		Spiritual interventions: A significant but moderate effects on spiritual well-being, meaning of life and depression. Significant large effects on anxiety. Existential intervention: A significant moderate effect on meaning of life. Studies of > 7 sessions demonstrated significant moderate-to-large effects on all study outcomes except meaning of life. Interventions provided by nurses showed significant large effects on all outcomes except anxiety. Interventions provided by other professionals (e.g., clinical psychologist, psychiatrist) demonstrated a significant but small effect only on anxiety.

			Format: Individual approach (n=10), combined individual and group approach (n=1). **Sessions**: 1–12 times, duration of 2 days–16 weeks. Length of the sessions 15–60 min.		
Oh & Kim 2016 **Korea** **Psychosocial** **AMSTAR 8 / 11**	Adults with cancer RCTs (n= 19) nonrandomised trials (n = 1)	To estimate the effect of expressive writing (EW) interventions on physical, psychological, and cognitive outcomes	**Provider:** A nurse **Type:** EW (Patients write for 20 minutes for 4 consecutive days about their deepest emotions and thoughts regarding traumatic experiences. **Format:** At home with researcher's (RN) guidance **Sessions:** 3–6 sessions, time 15–90 minutes per session, the duration of the intervention 3 days– 6 weeks, one-week interval (n = 8) and one-day interval (n = 7) were common.	Usual care	Physical: A significant small effect on relieving cancer symptoms; a significant small effect on physical outcomes fatigue, pain, and sleep disturbance. Psychological: Non-significant effects on psychological outcomes for anxiety, depression, perceived stress or distress, mood disturbance and QoL. In subgroup analysis a significant effect on QoL in the intervention group vs the control group. Cognitive: No significant effects on cognitive outcomes on intrusive thoughts and avoidance behaviors. Cancer survivors as a target population is recommended for an EW intervention for they have relatively less symptom distress and may be more comfortable writing.
Rodin et al. 2007 **Canada** **Interventions supporting patients' coping** **AMSTAR 7 / 11**	Cancer patients diagnosed with major depression Nonpharmacological RCTs, (n = 5)	To evaluate the efficacy of pharmacological and non-pharmacological care for depression.	**Provider:** A nurse **Type:** 1) A multi-component nurse-led intervention including a structured diagnostic interview consisting of education of depression, problem-solving therapy, consideration of anti-	Usual care Relaxation therapy	1) A reduction in both diagnoses of major depression and in depressive symptoms in intervention group compared to the usual care at three (p = 0.001) and six months (p = 0.006). 2) A greater improvement in depressive symptoms in intervention group (p = 0.001) 3) A significantly higher scores on the fighting spirit, lower scores on the helplessness measure, no

	Pharmacological RCTs, (n = 7 (excluded from this review)		depressant therapy through discussion with the general practitioner, coordinating and monitoring treatment. 2) Orientation program + usual care 3) Adjuvant psychotherapy 4) Group psychotherapy + relaxation **Sessions:** 10–30 min **Format:** group or individual		significant differences in depressive symptoms and mental adjustment to cancer. 4) No significant difference to those receiving relaxation therapy alone.
Hersch et al. 2009 Australia **Educational** **AMSTAR 6 / 11**	Women diagnosed with gynecological cancers (n = 7) (11 reviews excluded for provider non-nurse)	To summary the effectiveness of psychosocial interventions in women with gynecological cancers	**Provider:** Nurse **Type**: 1) Individualised discussion with reference to booklet, 2) Clinical nurse specialist (CNS) trained in psychosexual care provided sessions at home offering information and support, 3) CNS contacts 4) CNS contacts 5) video 6) evidence-based symptom management 7) APNs individually tailored specialised care **Sessions:** 1) Individualised discussion 25 min. 2) CNS sessions at least 3 times prior surgery, 3) CNS contacts eight times within four weeks after surgery, 4)	Attention control Usual care Booklet and one session with counsellor Information	1) Individualised discussion (25 min.): no group differences for barriers, side effects, pain intensity and interference, quality of life, adequacy of analgesic use. 2) CNS sessions at home: significantly less anxiety about sex, less sleep disturbance, and better global health status. 3) CNS contacts during eight weeks after surgery: non-significant effect on distress. 4) CNS contacts: non-significant differences 5) Videotape: non-significant effect on body-image and self-esteem. 6) Six times 45min. weekly sessions less worsening of symptom distress. 7) APN contacts: improved uncertainty but not physical health, depression, and distress.

			CNS contacts during eight weeks after surgery, 5) videotape of make-up techniques and hairpieces, 6) six weekly sessions (each 20–30 min), 7) APN contacts 18 times (home visits, phone calls, clinic visits).		
Jacobsen et al. 2007 **USA** **Psychological** **Activity based** **AMSTAR 6 / 11**	Adults with cancer RCTs (n = 30)	To provide evaluation of the efficacy of activity-based (n=17) and psychological (n=24) interventions against cancer related fatigue (CRF) and vigor.	**Provider:** NR **Type:** Psychological interventions (24): cognitive–behavioral forms of therapy, educational programs, supportive-expressive group therapy supportive forms of therapy. Activity based interventions (17): included exercise recommendations, different type (e.g., aerobic or resistance) and mode (e.g., walking or cycle ergometer) **Format:** Of the psychological interventions, 37 % were group format. Of exercise interventions, 39% were supervised and 61% home-based. **Sessions:** Numerous differences across in type, mode, and intensity of exercise.	Usual care	Psychological interventions: a statistically significant effect for CRF but not vigor. A significant effect of group-based but not individual interventions. Evidence of efficacy was stronger for psychological interventions than for activity-based interventions. Of publications 10/24 (42 %) yielded at least on finding significant at $p \leq 0.05$ favoring IG. Of publications rated fair or good, 9/18 (50 %) yielded at least one finding significant at $p \leq 0.05$. Activity-based: Of publications 7/17 (41 %) yielded at least one finding significant finding at $p \leq 0.05$. Publications of fair / better in quality 7/16 yielded at least one finding significant at $p \leq 0.05$. Study provides limited support for clinical use of non-pharmacological interventions to prevent or relieve cancer-related fatigue.

Rueda et al. 2011 **Spain** **Educational** **Interventions supporting patients' coping** **Activity-based** **AMSTAR 10 / 11**	Patients diagnosed with lung cancer RCTs (n = 15)	To assess the effectiveness of non-invasive interventions in improving symptoms, psychological functioning and QoL	**Provider:** Nurse **Type:** 1) Nursing interventions to manage breathlessness (3): rehabilitation techniques, the emotional experience of symptoms, breathing exercise, pacing, anxiety management and relaxation + written and DVD/video material and a call from the therapist a week after the last training session 2) Nursing programs (4): symptomatology, psychosocial well-being, QoL, satisfaction, anxiety, depression, symptom palliation. Nurse follow-up programs vs physician follow-up. Nurse educational programs 3) Nutritional interventions (1) 4) Psychotherapeutic, psychosocial, and educational interventions (3) and counselling 5) Exercise (3) 6) Reflexology (2) **Format:** NR **Sessions:** NR	Usual care	1) Nursing interventions: Significant differences at baseline between IG and CG for distress caused by breathlessness, difficulty in performing activities of daily living and anxiety, with the intervention group scoring higher for each of these variables. 2) Nursing programs: No significant differences between nurse-led and conventional medical follow-up on QoL or patient satisfaction. A statistically significant difference over time between the psychoeducational intervention and control group on symptom of anxiety, breathlessness, and fatigue. 3) Nutritional interventions: Effective in increasing caloric intake but a limited effect on weight. 4) Psychotherapeutic, psychosocial, and educational interventions: Counselling improved the QoL at 3, 6, 9 and 12 months. Depression, life satisfaction and self-esteem were significantly improved. 5) Exercise: Significant differences for power in favor of the IG, but not in hope. Non-significant change in QoL. Exercise tolerance and strength improved in IG 6) Reflexology: A significant reduction in anxiety and pain in IG.

Zhou et al. 2015 **Australia** **Educational** **AMSTAR 8 / 11**	Adult patients experiencing cancer-related pain Experimental, quasi-experimental and RCT studies (n = 6)	To analyse the effects of nurse-led educational interventions on improving cancer pain outcomes	**Provider:** A nurse **Type:** The 'Passport to Comfort' intervention, The Norwegian version of the PRO-SELF© Pain Control Program (PEPs), coaching, and The Representational Intervention for Cancer Pain (RIDcancerPAIN+) (no detailed description). **Format:** home visits, telephone, individual or group sessions **Sessions:** duration 20 min. to 90 min., lenght 6 weeks–6 months **Format:** NR **Sessions:** NR	Usual care	Educational interventions: Significantly better knowledge of pain in the IG. Longer intervention times produced higher knowledge levels (2/6). Better-educated oncology patients have lower attitudinal barriers and adhere better to analgesics usage. Non-significant change in QoL. Non-significant impact on pain relief. RIDcancerPAIN+ programme decreased long-term pain severity. Non-statistical difference on patient anxiety and depression (1/6). A multicomponent intervention (depression education up to ten 30-min. sessions of problem-solving therapy, consideration of antidepressant therapy through discussion with the general practitioner and coordinating and monitoring treatment) reduced significantly both diagnoses of MD and depressive symptoms.
Xu et al. 2019 **China** **Educational** **AMSTAR 9 / 11**	Adult patients with cancer of any stage and type. RCTs (n = 15) (n = 13 for meta-analysis)	To integrate the effect of e-health based self-management on cancer related fatigue (CRF), self-efficacy, and QoL.	**provider:** NR **type:** E-health based health care at least 2 of following: information provision, goal setting, behavior management and communication. **Format:** Smartphone / telephone / computer / electronic equipment **Sessions:** Duration 4 weeks–6 months	Non-e-health based control groups Waiting list or usual care	Statistically significant but small effect on CRF and self-efficacy, non-significant effect on QoL.

Son et al. 2018 **Korea** **Psychosocial** **AMSTAR 10 / 11**	Patients with colorectal cancer RCTs (n = 8)	To examine the effect of psychosocial interventions on QoL.	**Provider:** RN, health care worker or psychologist **Type:** psychological (cognitive behavioral therapy, psychotherapy, counseling, supportive therapy, motivational interviewing) or social (social skills training) support. **Format:** coaching, telephone interviews, counseling, and meetings; f-to-f (5) non-f-to-f (3) **Sessions:** duration < 1 month; 1–3 months > 3–6 months		No significant effect on QoL in most of the interventions. Only one study had a statistically significant benefit on QoL. It included 4 components: telephone delivered health coaching sessions over 6 months, a participant handbook, regular motivational postcards, and a pedometer. FACT-C was measured at 6 and 12 months. Face-to-face sessions showed a small effect size in QoL compared to non-face-to-face sessions. The longer the duration of the intervention the larger the effect size, but associations were non-significant.
Li et al. 2018 **China** **Interventions supporting patients' coping** **AMSTAR 7 / 11**	Patients with any type of cancer RCTs (n = 9)	To evaluate the efficacy of nursing interventions to increase the level of hope in cancer patients.	**Provider:** health care personnel (RN 6) or other professionals (therapist 3). **Type:** short-term-life-review; forgiveness therapy; Living with hope- program; Learning to live with cancer; solution focused approach, personal constructed group therapy; dignity therapy; health behavior intervention **Format:** Individual approach (7) and group format (2), at home or at hospital. **Sessions:** Mean length 3 weeks. Time ranged 30–120 min.	Usual care	Nursing interventions delivered by health care personnel can significantly improve the level of hope. Nurses encourage the patients to construct and rebuild appropriate strategies to enhance hope, find meaning within a life threating illness, and dictate their ability to cope with the disease in a meaningful way.

Zhang et al. 2018 **China** **Interventions supporting patients’ coping** **AMSTAR 10 / 11**	Patients with breast cancer and cancer survivors RCTs (n = 14)	To evaluate the effectiveness of telephone-based interventions on health-related quality of life and prognostic outcomes.	**Provider:** nurse **Type:** telephone interview of home nursing, physical activity intervention, health education or emotional expression intervention, selfcare, symptoms management and education of the use of audiotaped cognitive-behavioural strategies **Format:** telephone **Sessions:** programmes ranged from 3 weeks to 13 months, frequency of classes varied from one session per month to six sessions per week.	Usual care	Statistically significant results were found on anxiety (SMD = −0.16, 95% CI [0.01, 0.30] p = .04), self-efficiency (SMD = 0.22, 95% CI [−0.34, −0.10] p = .0004), social-domestic function (SMD = 0.19, 95% CI [−0.35, −0.03] p = .02) and quality of life (SMD = 0.54, 95% CI [−1.00, −0.08] p = .02). Non-significant effect on physiological function, depression, fatigue. Telephone-based interventions should be offered routinely to women diagnosed with breast cancer.
Tang et al. 2020 **China** **Psychological** **AMSTAR 8 / 11**	Breast cancer patients RCTs (n = 18)	To demonstrate the impact of cognitive behavioral stress management (CBSM) on breast cancer patients.	**Provider:** NR **Type:** cognitive-behavioral therapy and relaxation training **Format:** F-to-f or group based, web-based CBSM (n=2) **Sessions:** 2-hour sessions of peer work over 10 weeks; 20 or 5 weeks (in 2 RCTs)	One week psychoeducation seminar (10) Wait list (4)	Primary outcomes: Stress (n = 2): non-significant differences btw groups (WMD -0.52, 95% CI -1.42, 0.37) p=.25. Mood (n = 3): significantly greater relaxation vs CG (WMD 0.37, 95% CI, 0.16, 0.58) p<.01. Serum cortisol (n = 3): significantly lower levels after 12 months (WMD -0.07, 95% CI -0.14, -0.01) p<.05. Secondary outcomes: Anxiety (n = 3): a significant lower anxiety (n = 2) or non-significant difference (n=1) Depression (n = 5): significantly greater decrease (n = 4) or non-significant difference (n = 1). Conflicting findings in benefit finding, positive effect thought avoidance and intrusion and negative mood. Limitations: small sample sizes, methodological assessment was obscured due to lack of reporting.

Kim et al. 2021 **Korea** **Educational** **AMSTAR 9 / 11**	Patients with any type of cancer (preoperative) RCTs (n = 5) Non RCTs (n = 5)	To estimate the effects os preoperative education intervention on physical, cognitive, and affective outcomes.	**Provider:** RN (6), multidisciplinary board members including RN (1), physicians or surgeons (3) **Type:** educational intervention **Content:** type of surgery, preparation, complications, alternative to standard treatments, pain, postop. management **Format:** verbal (2), written (3), audiovisual (2) written audiovisual (3) **Sessions:** duration 15-90 min.		Overall effect size was moderate (0.49, SE 0.14). Knowledge (n = 5): (SMD 0.94; 95% CI, 0.08 to 1.80, p=.03) Satisfaction (n = 6): (SMD 0.53; 95% CI, 0.11 to 0.96; p =.01) Depression (n = 2): (SMD 0.05; 95% CI, -0.21 to 0.32; p =.71) QoL: physical domain (n = 3) (SMD 0.1;95% CI, -0.10 to 0.30), role domain (n = 3) (SMD 0.05; 95% CI, -0.15 to 0.25), emotional domain (n = 3) (SMD -0.01 to 0.19), cognitive domain (N = 2) (SMD -0.01; 95% CI, -0.28 to 0.26), social domain (n = 3) (SMD 0.03; 95% CI, -0.17 to 0.23) and Global health domain (n = 4) (SMD 0.06; 95% CI, -0.07 to 0.19). Decision making (n=3): (SMD -0.08; 95% CI, -0.24 to 0.09; p = 0.36) Anxiety: (SMD -0.38;95% CI, -0.95 to 0.20; p = 0.2) Pain: (n = 4) (SMD -0.6; 95% CI, -0.99 to -0.21). Effect was greater in younger age groups using verbal or combined educational methods. Using verbal education (n = 2) (SMD 1.08; 95% CI, 0.48 to 1.68) or written audiovisual education (n=3) (SMD 0.73; 95% CI, 0.01 to 1.45) yielded greater effects compared with audiovisual (n = 2) (SMD 0.16; 95% CI, -0.04 to 0.36) and written education (n = 3) (SMD 0.1; 95% CI, -0.06 to 0.25). Duration of being 15–30 min.(n=5) (SMD=0.63; 95% CI, 0.21-1.05) and 60–90 min. (n=2) (SMD=0.14; 95% CI, -0.14 to 0.42) did not affect the effect sizes.
Ream et al. 2020 **United Kingdom** **Educational**	Patients with any type of cancer across the disease trajectory.	To assess the effectiveness of telephone-based interventions for reducing	**Provider:** nurses (24) or other professionals (9) **Type**: Educational interventions	Usual care with additional support	21 / 32 studies reported a significant effect (P< 0.05) in favor of the IG. Meta-analyses were not possible for any of the outcomes due to heterogeneity. Anxiety (n=16): statistically significant effect (n=5), no significant effect (n=6)

AMSTAR 11 / 11	RCTs or quasi-RCTs (n = 32)	symptoms associated with cancer and its treatment.	**Format:** Telephone (10); with additional elements (16) i.e., face-to-face consultations and digital/online/ printed resources. Telephone calls with f-to-f sessions (2). Telephone calls with both f-to-f sessions and digital/printed materials (3). Automated symptom monitoring and prescribing recommendations (1). **Sessions:** Frequency varied across studies, e.g., weekly (18), every 2. weeks (2), three calls over three (1) or four calls over two (1) successive cycles of CTX, series of calls with increasing time intervals (7), etc. Number of calls 1–18 (mostly 3–4). Duration 10–70 min.	Two telephone interventions against each other (n=8)	Depression (n=21): significant effect (n=8), borderline significance (n=1), no significant effect (n=3). Fatigue (n=9): no evidence of differences (n=4), statistically significant effect (n=5), Emotional stress (n=7): no significant effect. Uncertainty (n=3): statistically significant effect (n=2), no significant effect (n=1). Pain (n=6): significant effect (N=3) no significant effect (n=3) Dyspnea (n=3): significant effect (n=1) no significant effect (n=1) Sexually related symptoms (n=NR): significant effect (n=2) no significant effect (n=1). Confidence in the evidence is very low. It is unclear whether telephone interventions alone, or combined with face-to-face meetings, or printed or audio materials, are most effective in reducing symptoms.
Ahmad et al. 2020 Jordan **Psychosocial** **AMSTAR 9 / 11**	Adult patients with any type of cancer RCTs (n = 7)	To analyse the effectiveness of virtual reality technology (VR) for management of pain and anxiety	**Provider:** NR **Type:** immersive or non-immersive VR **Format:** during chemotherapy or hospitalisation **Sessions:** duration ranged from 45–90 min. during	Usual care	VR plus standard care were more effective in reducing anxiety especially in adult and elderly patients undergoing anti-cancer treatments and during their hospitalisation. Anxiety (n=6 adults): A significant reduction of the anxiety level immediately after chemotherapy or radiotherapy sessions with VR (n=3, all adult or elderly). Non-significant difference in anxiety levels between the intervention and control groups (n=3).

			chemotherapy, 30 min. during hospitalisation.		The effectiveness in reducing pain or anxiety during hospitalisation among adults and elderly a significant reduction of pain (n=2). Using VR as an adjuvant was more effective than morphine alone in relieving pain and anxiety among hospitalized patients with breast cancer (n=1).

Appendix 4. Knowledge test RASoma.

KNOWLEDGETEST OF MALNUTRITION, CHEMOTHERAPY INDUCED NUTRITION-IMPACT SIDE EFFECTS AND THEIR SELF-CARE

Purpose of this knowledgetest is to assess level of knowledge related to malnutrition and chemotherapy-induced nutrition imapact side- effects and their self-care. It is important that You answer to items based on your current knowledge by choosing ’right’ or ’wrong’. It takes about three minutes to answer.

1.	Malnutrition is lack of energy and protein.	Right	Wrong
2.	Malnutrition is rare in patients with colorectal cancer during chemotherapy.	Right	Wrong
3.	Malnutrition reduces the ability to cope with chemotherapy.	Right	Wrong
4.	Malnutrition increases the risk of developing infections.	Right	Wrong
5.	If the mouth is sore and dry, swallowing can be alleviated by soft or moist food.	Right	Wrong
6.	Cold sensitivity can be alleviated by taking the fluids cool.	Right	Wrong
7.	Eating vegetables and fruits does not prevent constipation.	Right	Wrong
8.	Eating should be avoided during diarrhoea.	Right	Wrong
9.	Fatigue is stronger if you do not eat enough.	Right	Wrong
10.	Strong anxiety can prevent you from eating enough.	Right	Wrong
11.	Nausea will be relieved if you don’t eat.	Right	Wrong
12.	Pain in the stomach prevents you from eating enough.	Right	Wrong
13.	Eating small portions of food often helps to treat loss of appetite.	Right	Wrong
14.	When you eat something sour, your heartburn eases.	Right	Wrong
15.	Cooking food well can facilitate taste changes.	Right	Wrong

Appendix 5. Summary of the evidence of the effectiveness (modified from Paper I).

Outcome	**Interventions and effect (+ / 0 /-)**					**Author, year**
	Educational	Psycho-social	Psycho-logical	Multi-component	Activity- based	
QoL	**+**					Hersch et al. 2009
		0				Oh & Kim 2016
		0 / +				Son et al. 2018
	0			0/+		Cook et al. 2014
				+		Zhang et al. 2018
	0					Hersch et al. 2009; Zhou et al. 2015; Xu et al. 2019, Kim et al. 2021
				0	0	Rueda et al. 2011
Spiritual well-being		+				Oh & Kim 2014
Satisfaction with care	+					Cook et al. 2014, Kim et al. 2021
				+		Rueda et al. 2011
				+		Cook et al. 2014
Meaning of life		+				Oh & Kim 2014
Hope				+		Li et al. 2018
					0	Rueda et al. 2011
Empowerment					0	Rueda et al. 2011
Anxiety				+		Rueda et al. 2011, Zhang et al. 2018
		+				Oh & Kim 2014
		0				Oh & Kim 2016
		0/+				Ahmad et al. 2020
	0					Hersch et al. 2009, Cook et al. 2014., Kim et al. 2021

Outcome	Interventions and effect (+ / 0 /-)					Author, year
	Educational	Psychosocial	Psychological	Multi-component	Activity- based	
			0/+			Tang et al. 2020
	0/+					Ream et al. 2020
Anxiety about sex	+					Hersch et al. 2009
Distress	+					Coolbrandt et al. 2014
	0/+					Hersch et al. 2009
	0					Ream et al. 2020
				+		Rueda et al. 2011
		0				Oh & Kim 2016
			0			Tang et al. 2020
Symptom severity	+					Hersch et al. 2009; Coolbrandt et al. 2014
Fatigue		+				Oh & Kim 2016
				+		Rueda et al. 2011
	+					Xu et al. 2019
	0/+					Ream et al. 2020
					+	Jacobsen et al. 2007
			+			Jacobsen et al. 2007
				0		Zhang et al. 2018
Vigor			0			Jacobsen et al. 2007
Depression	0					Hersch et al. 2009; Cook et al. 2014, Kim et al. 2021
	0/+					Ream et al. 2020
		+				Rodin et al. 2007

Outcome	**Interventions and effect (+ / 0 /-)**					**Author, year**
	Educational	Psycho-social	Psycho-logical	Multi-component	Activity- based	
				+		Rodin et al. 2007
				0		Rodin et al. 2007, Zhang et al. 2018
		+				Oh & Kim 2014
		0				Oh & Kim 2016
			0/+			Tang et al. 2020
BreathlessnessDyspnea				+		Rueda et al. 2011
	0/+					Ream et al. 2020
Sleep disturbance		+				Oh & Kim 2016
				+		Cook et al. 2014
	+					Hersch et al. 2009
Mood disturbance		0				Oh & Kim 2016
			+			Tang et al. 2020
Self-efficacy	+					Xu et al. 2019
Self-efficiency				+		Zhang et al. 2018
Coping				+		Cook et al. 2014
Attitudes	+					Zhou et al. 2015
Pain relief	0					Zhou et al. 2015
	+					Kim et al. 2021
	0/+					Ream et al. 2020
		+				Oh & Kim 2016, Ahmad et al. 2020
The level of knowledge	+					Zhou et al. 2015, Kim et al. 2021
Decision making	0					Kim et al. 2021

Outcome	**Interventions and effect (+ / 0 /-)**					**Author, year**
	Educational	Psycho-social	Psycho-logical	Multi-component	Activity- based	
Pain management barriers	0					Hersch et al. 2009
Sexual functioning	+					Hersch et al. 2009
Sexually related symptoms	0/+					Ream et al. 2020
Uncertainty	+					Hersch et al. 2009
				0/+		Cook et al. 2014
	0/+					Ream et al. 2020
Body image, body esteem	+					Hersch et al. 2009; Cook et al. 2014
Fighting spirit		+				Rodin et al. 2007
Helplessness		+				Rodin et al. 2007
Intrusive thoughts		0				Oh & Kim 2016
Avoidance behaviors		0				Oh & Kim 2016
Functional ability				+		Rueda et al. 2011
				0		Zhang et al. 2020
					0	Rueda et al. 2011

Appendix 6. Change in primary and secondary outcomes (from original manuscript IV).

Variable	Participants	Group				
		IG	CG			
	IG / CG (n)	Mean (SD) or median [IQR]	Mean (SD) or median [IQR]	Mean difference (95%CI) or Median difference [95%CI] ^{c}	*p*–value	Effect size
PAM, baseline	43/40	56.7 (9.10)	59.6 (14.43)	–2.86 (–8.10, 2.37)	0.288 ^{a}	–0.24
PAM, follow-up	43/40	60.5 (12.90)	58.9 (12.13)	1.59 (–3.89, 7.06)	0.565 ^{a}	0.13
PAM, change	43/40	3.77 (10.42)	–0.67 (10.80)	4.45 (–0.19, 9.09)	0.060 ^{a}	0.42
RasOma, baseline	43/39	13.00 [2.00]	14.00 [2.00]	–1.00 [–1.00, 0.00]	0.038 ^{b}	–0.43
RasOma, follow-up	43/40	13.00 [2.00]	14.00 [2.00]	0.00 [–1.00, 0.00]	0.084 ^{b}	–0.41
RasOma, change	43/39	0.00 [2.00]	0.00 [1.00]	0.00 [–1.00, 1.00]	0.99 ^{b}	–0.10
NRS2002, baseline	40/40	1.00 [1.00]	2.00 [2.00]	0.00 [–1.00, 0.00]	0.089 ^{b}	–0.51
NRS2002, follow-up	40/40	1.50 [1.00]	2.00 [1.00]	0.00 [–1.00, 0.00]	0.348 ^{b}	–0.23
NRS2002, change	40/40	0.00 [1.00]	0.00 [1.00]	0.00 [0.00, 1.00]	0.152 ^{b}	0.33
FACT–C, baseline	41/36	104.8 (14.2)	106.9 (17.10)	–2.14 (–9.24, 4.97)	0.551 ^{a}	0.14
FACT–C, follow-up	41/37	100.9 (16.8)	105.9 (18.20)	–4.99 (–12.9, 2.90)	0.211^{a}	–0.29
FACT-C, change	39/35	–4.03 (15.8)	–0.77 (11.60)	–3.26 (–9.7, 3.20)	0.319 ^{a}	–0.23

Abbreviations: PAM, the Patient Activation Measure; RasOma, the knowledge test; NRS2002, the Nutritional Risk Screening; FACT–C, the Functional Assessment of Cancer Therapy–Colorectal. Effect size was calculated using Cohen's D, the mean difference / the pooled standard deviation; ^{a} Independent Samples T Test; ^{b} Mann–Whitney U Test; ^{c} Hodges–Lehman estimate for median difference. SD = standard mean difference; IQR = interguartile range; MD = median difference; CI = confidence interval. IG = Intervention group, G = Control group.

Appendix 7. Factors associated with the change in activation level (fron original manuscript IV).

	n	Adjusted mean (standard error)	Adjusted mean difference (95 % CI)	*p*–value [a]
Gender				
Female	40	–0.97 (1.6)		
Male	43	3.9 (1.6)	4.86 (0.32, 9.4)[b]	0.036*
Age				
Under 60	33	0.25 (1.8)		
Over 61	50	2.4 (1.5)	2.16 (–2.6, 6.9)[c]	0.367
Education level				0.829
Comprehensive	12	1.47 (3.1)	–4.6 (–14.4, 5.3)[d]	0.780
Intermediate	16	6.04 (2.7)	5.6 (–5.3, 14.4)[e]	0.780
University	54	0.39 (1.4)	–1.1 (–13.0, 1.7)[f]	0.196
Dependents				
No	73	1.70 (1.3)		
Yes	7	1.80 (4.1)	0.10 (–8.4, 8.6)[g]	0.981
Residence				
Alone	20	2.68 (2.4)	1.1 (–6.4, 8.2)[h]	1.00
With another person	44	1.58 (1.6)	–1.1 (–6.3, 8.4)[i]	1.00
With family	18	0.53 (2.5)	–2.1 (–10.7, 6.4)[j]	1.00
Employment				
At work	36	0.62 (1.8)		
Not at work	46	2.40 (1.6)	1.8 (–3.0, 6.5)[k]	0.458
Prevalence to other organs				
No	47	3.46 (1.5)		
Yes	36	-0.97 (1.8)	–4.4 (–9.1, 0.2)[l]	0.061
Side effects				
1–6 side effects	15	2.12 (2.8)		
7–13 side effects	27	0.17 (2.1)	–1.95 (–8.9, 5.0)[m]	0.575
Emergency room visits				
No	69	1.8 (1.3)		
Yes	14	0.6 (2.9)	–1.2 (–7.4, 5.0)[n]	0.703
Stoma				
No	67	1.3 (1.3)		
Yes	16	2.7 (2.7)	1.4 (–4.5, 7.3)[o]	0.644

Abbreviations: [a] Analysis of variance, adjusted for group, [b] male vs female, [c] < 60 years vs > 60 years, [d] comprehensive vs intermediate, [e] intermediate vs university, [f] university vs comprehensive, [g] dependents vs no dependents, [h] alone vs with another person, [i] with another person vs with family, [j] with family vs alone, [k] at work vs not at work, [l] not spread vs spread to other organs, [m] 7–13 side effects vs 1-6 side effects, [n] no visits to emergency room vs visits, [o] no presence of stoma vs stoma. * Significant at 0.05 level. CI = confidence interval.

Appendix 8. Factors associated with the change in risk of malnutrition (from original manuscript IV).

	n	Median (IQR)	MD (95 %CI) [a]	*p*–value
Gender				
Female	38	0.00 (0.00)		
Male	41	0.00 (2.00)	0.00 (0.00, 0.00)[d]	0.552 [b]
Age				
<60	32	0.00 (2.00)		
>60	47	0.00 (0.00)	0.00 (0.00, 0.00)[e]	0.910 [b]
Education level				0.444 [c]
Comprehensive	11	0.00 (1.00)	0.00 (0.00, 1.00)[f]	0.291 [b]
Intermediate	14	0.00 (1.00)	0.00 (–1.00, 0.00)[g]	0.291 [b]
University	53	0.00 (1.00)	0.00 (0.00, 1.00)[h]	0.617 [b]
Dependents				
No	71	0.00 (1.00)		
Yes	6	0.00 (1.25)	0.00 (0.00, 1.00)[i]	0.544 [b]
Residence				0.004 * [c]
Alone	19	0.00 (0.00)	0.00 (-1.00, 0.00)[j]	0.250 [b]
With another	43	0.00 (1.00)	1.00 (0.00, 1.00)[k]	0.076 [b]
With family	16	–1.00 (1.00)	1.00 (0.00, 1.00)[l]	0.001*
Employment				
At work	36	0.00 (2.00)		
Not at work	42	0.00 (0.00)	0.00 (0.00, 0.00)[m]	0.858 [b]
Prevalence to other organs				
No	45	0.00 (1.00)		
Yes	34	0.00 (1.00)	0.00 (0.00, 1.00)[n]	0.094 [b]
Side effects				
1–6	14	0.00 (0.25)		
7–13	27	0.00 (2.00)	0.00 (0.00, 1.00)[o]	0.694 [b]
Emergency room visits				
No	64	0.00 (0.00)		
Yes	14	1.00 (2.00)	0.00 (0.00, 1.00)[p]	0.216 [b]
Stoma				
No	63	0.00 (1.00)		
Yes	16	0.00 (1.75)	0.00 (–1.00, 0.00)[q]	0.611 [b]

Abbreviations: *Significant at 0.05 level. [a] Hodges–Lehmann estimate for median difference, [b] Mann Whitney U Test, [c] Kruskal-Wallis T test, [d] Female vs male, [e] under 60 vs over 61 years, [f] comprehensive vs intermediate, [g] intermediate vs university, [h] comprehensive vs university, [i] dependents vs no dependents, [j] alone vs with another person, [k] with another person vs with a family, [l] with a family vs alone, [m] at work vs not at work, [n] no prevalence to other organs vs prevalence to other organs, [o] 1–6 side effects vs 7–13 side effects, [p] no visits to emergency room vs visits to emergency room. [q] no presence of stoma vs stoma. IQR = interquartile range; MD = median difference; CI = confidence interval.

Appendix 9. Factors associated with the change in social well-being (from original manuscript IV).

	n	Median (IQR)	MD (95 %CI) [a]	*P*–value
Gender				
Female	39	0.50 (4.50)		
Male	43	0.00 (4.50)	–0.17 (–1.50, 1.00)[d]	0.583[b]
Age				
<60	33	0.00 (3.33)		
>60	49	1.00 (4.50)	1.17 (0.00, 3.00)[e]	0.044*[b]
Education level				0.663[c]
Comprehensive	12	-0.17 (2.29)	–1.00 (–3.83, 1.83)[f]	0.648[b]
Intermediate	15	1.00 (6.33)	0.00 (–2.33, 2.00)[g]	0.907[b]
University	54	0.33 (4.50)	–0.83 (–3.00, 0.83)[h]	0.341[b]
Dependents				
No	73	0.00 (4.25)		
Yes	7	1.17 (4.83)	0.67 (–2.00, 3.50)[i]	0.647[b]
Residence				0.001[c]
Alone	19	2.00 (3.00)	1.17 (–0.33, 3.00)[j]	0.111[b]
With another person	44	0.33 (4.50)	2.00 (0.83, 4.00)[k]	0.007[b]
With family	18	–1.00 (2.00)	3.08 (2.00, 5.00)[l]	0.000*[b]
Employment				
At work	36	0.00 (2.54)		
Not at work	45	1.17 (5.50)	1.42 (0.00, 3.00)[m]	0.025*[b]
Prevalence to other organs				
No	46	1.00 (5.00)		
Yes	35	0.00 (3.42)	–1.00(–2.00, 0.33)[n]	0.196[b]
Side effects				
1–6	15	1.50 (5.67)		
7–13	26	1.08 (4.50)	–1.00 (–3.42, 1.33)[o]	0.512[b]
Emergency room visits				
No	67	1.00 (4.50)		
Yes	15	–1.00 (1.75)	–2.00 (–3.50, 0.33)[p]	0.010*[b]
Stoma				
No	66	0.25 (3.50)		
Yes	16	0.00 (5.50)	0.17 (–1.00, 2.50)[q]	0.634[b]

Abbreviations: [a] Hodges–Lehmann estimate for median difference, [b] Mann Whitney U Test, [c] Kruskal-Wallis T test, [d] Female vs male, [e] under 60 vs over 61 years, [f] comprehensive vs intermediate, [g] intermediate vs university, [h] comprehensive vs university, [i] no dependents vs dependents, [j] alone vs with another person, [k] with another person vs with a family, [l] alone vs with a family, [m] at work vs not at work, [n] no prevalence to other organs vs prevalence to other organs, [o] 1–6 side effects vs 7–13 side effects, [p] no visits to emergency room vs visits to emergency room, [q] presence of stoma vs no stoma. IQR = interquartile range; MD = median difference; CI = confidence interval. *Significant at 0.05 level.

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