

Survivorship care plans for people with colorectal cancer: do they reflect the research evidence?

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ABSTRACT

Aim In the present study, we synthesized the published literature about the psychosocial aspects of colorectal cancer (CRC) survivorship to support an update of the evidentiary base of the survivorship care plans (SCPs) created in our jurisdiction.

Methods The psychosocial topics identified in the CRC SCPs created by two different initiatives in our province were used as search criteria: quality of life (QOL), sexual function, fatigue, and lifestyle behaviors. An umbrella review was conducted to retrieve the best possible evidence. Only reviews that investigated the intended outcomes in CRC survivors and those with moderate-to-high methodologic quality scores were included.

Results Of 462 retrieved reports, eight reviews met the inclusion criteria for the synthesis. Of those eight, six investigated the challenges of CRC survivors and two investigated the effect of physical activity on survivor well-being. Our results indicate that emotional and physical challenges are common in CRC survivors and that physical activity is associated with clinically important benefits for the fatigue and physical functioning of CRC survivors.

Conclusions Our study findings update the evidence and indicate that existing SCPs in our province concerning the physical and emotional challenges of CRC survivors reflect the evidence at the time of their issue. However, the literature concerning cancer risks specific to CRC survivors is lacking. Although systematic reviews are considered to be the “gold standard” in knowledge synthesis, our findings suggest that much remains to be done in the area of synthesis research to better guide practice in cancer survivorship.

Key Words Colorectal cancer, survivorship, survivorship care planning, psychosocial challenges

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BACKGROUND

Although better screening, early detection, and new treatment strategies result in better cancer survival rates, survivors and their families continue to face challenges once treatment is completed. In 2009, the Canadian Partnership Against Cancer made survivorship and survivorship care plans (SCPs) a practice and research priority, as the United States has^{1,2}. The SCP, a personalized record of care and follow-up that includes potential post-treatment issues, signs of recurrence, guidelines for lifestyle modifications, and important community resources, aims to improve patient-reported and health-related outcomes after treatment completion³. Plans can also be shared with the primary

care provider to promote coordinated ongoing care. The SCP seems to reduce anxiety on the part of survivors about what will happen to them after treatment completion; it also can improve communication between a survivor's cancer care providers and primary care providers^{4,5}.

There have been appreciable research and knowledge implementation efforts about survivorship—and more specifically, about SCPs—in the United States and the United Kingdom. The National Cancer Survivorship Initiative was started in the United Kingdom in 2008 and, in collaboration with the U.K. National Health Service and the Macmillan organization, has made progress in providing support services to those living with and beyond cancer, addressing individual needs and enhancing wellness⁶.

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Similarly, in the United States, the American Cancer Society, the Centers for Disease Control and Prevention, the LIVES-STRONG Foundation, and the National Cancer Institute have been collaborating to enhance the translation of survivorship research into evidence-based interventions⁷. Appreciable scholarly research into the topic has been accomplished, mostly focused on breast cancer patients and survivors^{3,8}. However, in Canada, research pertaining to the integration of survivorship care into primary care is much more recent in organization and publication^{9,10}. Our study of CRC SCPS, undertaken by two different teams of clinician–scientists in our province and reflecting current evidence about this population group, therefore provides new information and insight.

The contents of a SCP are often tailored to a specific type of cancer (and its location, spread, and treatment), although the treatment consequences can vary immensely. For example, CRC—also known as colon cancer, rectal cancer, or bowel cancer—is often treated with bowel resection and can also require adjuvant therapies such as chemotherapy or radiotherapy, or both^{11–13}. The occurrence of CRC and its treatment can significantly alter an individual's nutrition needs and eating habits, because the manner in which the body digests and absorbs food is affected^{14–16}. As a result, individuals who receive a CRC diagnosis face myriad challenges while moving from one phase of the cancer trajectory to another¹⁷ and will require specific information to better cope with the challenges. Although SCPS are apparently beneficial, there are pragmatic challenges in implementing them not only in CRC, but also across all disease groups. Examples include choosing a format, finding resources, managing time constraints, and allocating personnel¹⁸.

No patient information materials have been internationally or nationally accepted as suitable for all patients. As a result, many cancer care facilities develop their own materials, including the information resources that are part of SCPS, which can often lead to duplication of effort and, more importantly, inconsistencies in care provision. In fact, a study that evaluated 16 SCPS from several developed countries reported considerable variation in the SCPS with respect to their content and also their delivery approach¹⁹. In our province, two independent initiatives funded by different sources, led by clinician–researchers from two sites of the provincial agency responsible for cancer care, located in two different geographic regions, created SCPS for people with CRC with no or little coordination in terms of format, language, or content. Thus, the overall goal of the present study was to contribute to consistency in the provincial approach to survivorship care planning through knowledge synthesis and exchange. Our original research question was “Do the two SCPS independently created in our province reflect the highest level of research evidence pertaining to the psychosocial aspects of CRC survivorship?” Here, we report on the physical and emotional challenges of CRC survivors and the impact of the interventions that have been used for lessening those challenges. This review was part of a quality improvement project under the auspices of the Provincial Survivorship Program, aiming to support the production of evidence-based information materials to be available to health care professionals and their patients in our province.

METHODS

We conducted an umbrella review, a systematic review of systematic reviews²⁰ in accordance with the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines²¹.

Literature Search

A systematic search of the electronic databases MEDLINE, PsycINFO, Cochrane Library, CINAHL, and EMBASE using keywords and MESH terms, together with a hand search of the list of references of identified articles, was used to gather all the available literature concerning the outcomes of interest (Table 1) for the present review. The search terms used to identify the articles were “(colorectal, rectal, bowel, colon, intestinal, rectum OR lower gastrointestinal) AND (cancer, carcinoma OR neoplasms) AND (quality of life, well-being, mental health, QOL, HRQOL, life quality, life qualities, qualities of life, life satisfaction OR personal satisfaction, sexual dysfunctions, bowel dysfunctions) AND (cancer patients, OR cancer survivors) AND (physical activity, exercise) AND (diet, fiber, meat, red meat, processed meat, nutrition supplements, dairy) AND (spirituality, physiotherapy, sex therapy, education and information, cognitive therapies, psychotherapy, meditation or relaxation therapy).” The search was conducted during April and May 2013; it was updated in December 2014 and again in September 2015 by the first author with the support of the BC Cancer Agency–Vancouver Island Centre medical

TABLE 1 Outcomes of interest in the present review

1.	Factors that increase or decrease cancer risk ■ Diet (herbal and natural health products or supplements, calcium intake, multivitamin supplements, fibre intake, vegetarian and non-vegetarian diet) ■ Physical activity ■ Smoking cessation ■ Alcohol intake
2.	Emotional challenges to colorectal cancer patients and survivors ■ Anxiety, depression, stress, fear, sadness, and quality of life
3.	Physical challenges to colorectal cancer patients and survivors ■ Sexual, urinary, and bowel function or dysfunction ■ Fertility issues and concerns ■ Weight loss or gain ■ Body image
4.	Any of the following interventions used in colorectal cancer patients and survivors that affect their well-being ■ Physical activity ■ Diet ■ Physiotherapy ■ Sex therapy ■ Education and information ■ Psycho-educational therapies ■ Cognitive therapies ■ Meditation and relaxation therapies

librarian. Grey literature such as dissertations, theses, and conference and poster abstracts were included only if they contained a detailed description of the included studies and if outcomes of interest were assessed while meeting the inclusion criteria.

All identified citations were moved to an online bibliographic management program (RefWorks: ProQuest LLC, Ann Arbor, MI, U.S.A.). After duplicates were removed, each study was given an identification code. The first author and 2 patient support volunteers from a cancer clinic, who were trained in abstract selection, independently screened the abstracts. Once that step was complete, 2 review authors (VD, HD) read the remaining articles in full. Study quality was assessed for all those articles, and articles were eliminated if they did not meet the inclusion criteria.

Inclusion Criteria

Systematic reviews, meta-analyses, and other review types were included if they

- were conducted with at least 50 CRC survivors,
- reported any of the outcomes of interest, and
- had at least a moderate quality score (≥ 5).

Studies conducted with a mixed group of cancer patients were included only if they reported the measured outcomes separately for CRC survivors.

Quality Assessment

The quality of the included studies was assessed using AMSTAR²², a reliable and valid measurement tool to assess the methodologic quality of systematic reviews^{23,24}. Using AMSTAR, the quality of systematic reviews is characterized at three levels: scores of 0–4 are considered to reflect poor quality; 5–7, moderate quality; and 8 and above, high quality. For the present work, all potentially eligible studies were scored independently by 2 authors (VD, HD). Discrepancies were resolved by joint discussion, and if needed, the 3rd author (AK) was consulted. Studies with a quality score of 5 or greater were included in the review.

Outcomes of Interest

Based on our analyses of the SCsPs created by the two provincial groups of clinician scientists, we categorized outcomes of interest into 4 large groups:

- Factors that increase or decrease the cancer risk in CRC survivors
- Emotional challenges of CRC survivors
- Physical challenges of survivors
- Any interventions used with CRC patients and survivors, and the effect of those interventions in terms of survivor well-being

Table 1 presents those outcomes of interest in detail.

Data Extraction and Synthesis

Data from the selected scientific reviews was independently extracted by 2 review authors (VD, HD) using a pre-agreed data extraction form: title of the paper, author, year of publication, source, and country; type of study, cancer

type, cancer stage, and location of tumour; sample size and distribution in each arm; description of the intervention, study setting, length and frequency of intervention, duration of follow-up, and control intervention characteristics; outcomes measured and outcome assessments. Given the exhaustive nature of the umbrella review and the diversity of the outcomes investigated, quantitative analyses were not feasible.

RESULTS

The search strategy identified 462 reviews, of which 72 were read in full and quality-assessed. Although forty reviews met the inclusion criteria with respect to quality assessment, twenty-nine studies were eliminated because they were investigating the primary CRC risk in general populations^{25–53}, and another three systematic reviews were eliminated because the original studies included in those reviews were of poor quality due to numerous methodologic flaws and inconclusive findings^{54–56}. Thus, only the remaining eight reviews (seven systematic reviews and one meta-analysis) were included in our synthesis^{57–64}. Figure 1 presents details of the search and inclusion and exclusion process.

Study Characteristics

Table II presents the characteristics of the included studies, their overall findings, and quality scores; Table III presents their flaws and limitations. Of the eight included reviews, six investigated the challenges of CRC patients or survivors (QOL, sexual and bowel dysfunctions)^{59–64}, and two investigated the effect of physical activity on the well-being of CRC survivors^{57,58}. No reviews for the population of interest were found that investigated cancer risk; urinary problems, fertility concerns, body image, weight-gain issues, concerns about diet or nutrition, or spirituality; or interventions such as physiotherapy, sex therapy, education and information provision, cognitive therapies, meditation, or relaxation therapies. No effect size was described in any of the reviews. The information extracted was therefore synthesized qualitatively and is summarized in the subsections that follow.

QOL

Three reviews investigated the QOL of CRC survivors^{60–62}. In one review, Jansen *et al.* compared the QOL of 2187 CRC survivors (≥ 5 years post diagnosis) with that of the general population, reporting that the overall QOL of CRC survivors was comparable to that of the general population, although the physical QOL of CRC survivors was comparatively poorer. In addition, CRC survivors frequently experienced higher levels of anxiety, distress, and long-term treatment-related complications such as bowel dysfunctions that could affect QOL⁶⁰. Another review (eight studies) investigated the effect of intensified follow-up programs with 2142 CRC survivors treated surgically⁶¹. Of the eight studies, six were included in the meta-analysis, and the findings showed that intensified follow-up programs were associated with survival benefit (odds ratio: 0.73; 95% confidence interval: 0.59 to 0.91), but had no effect with respect to QOL⁶¹. The authors of the third review investigated QOL in 3675 rectal cancer patients who underwent either of the 2 CRC curative

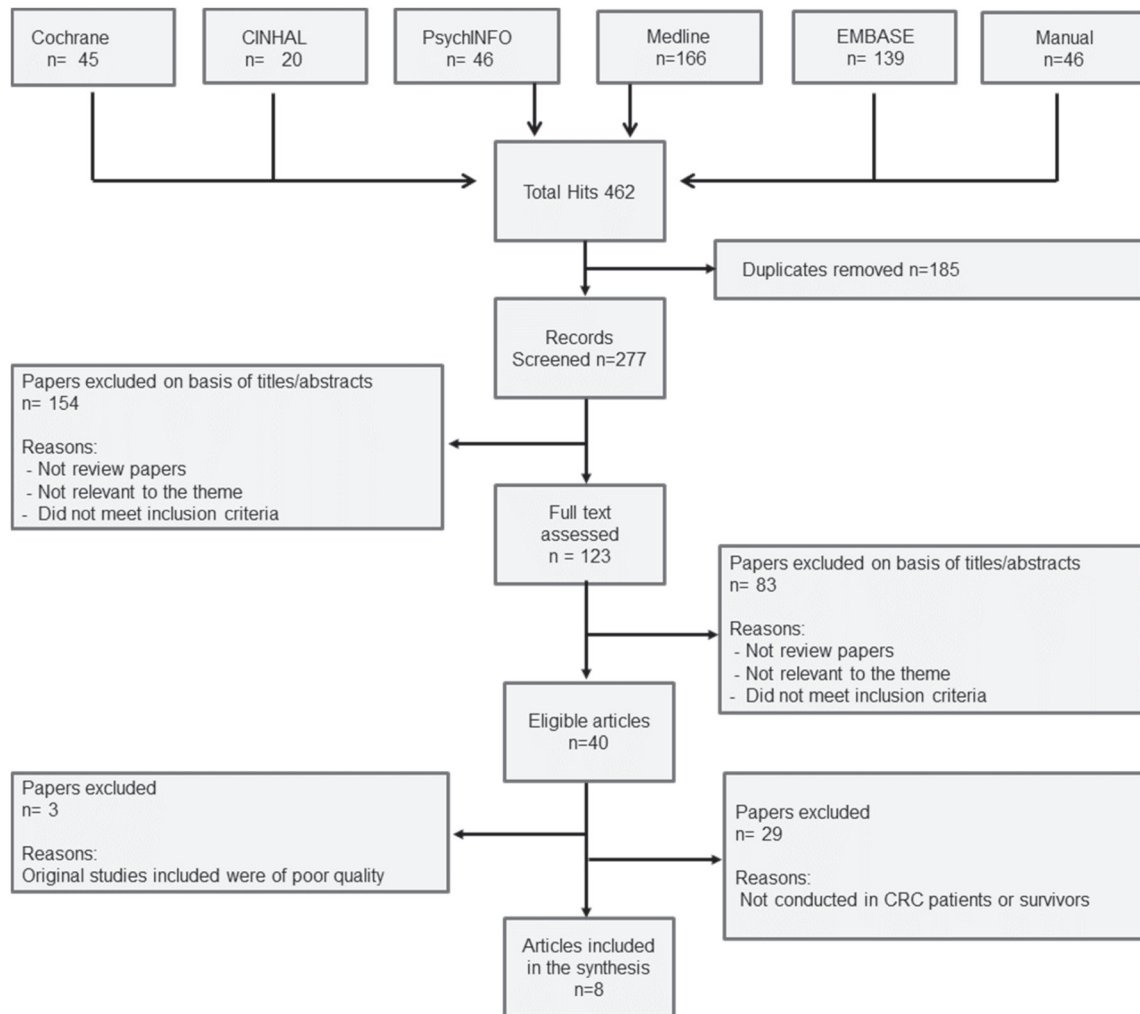


FIGURE 1 The process of searching for and selecting reliable articles in the literature.

surgeries: an abdominoperineal excision (APE) or Hartmann operation (both leading to a permanent stoma), and anterior resection (AR)⁶². Although no differences were found in the general QOL of patients who underwent either of the surgeries, poorer physical and social functioning, more severe sexual dysfunctions, and poorer body image were experienced by those who underwent APE than by those who underwent AR. Compared with patients who underwent APE, those who underwent AR were more nervous and experienced more fear of death.

Sexual Dysfunction

Two reviews investigated sexual dysfunction in CRC survivors^{59,64}. According to both reviews, sexual dysfunctions were the most frequently observed treatment-related complications in CRC survivors, although the signs and symptoms and the degree of severity varied from person to person and by sex, tumour location, and treatment received. Erectile or ejaculatory dysfunctions (or both) were common among male survivors; female survivors frequently experienced dyspareunia, vaginal dryness, and inability

to reach orgasm⁶⁴. One review of 6247 CRC survivors who underwent surgery reported that the percentage of preoperatively potent men who experienced sexual dysfunction postoperatively ranged from 5% to 88% and that about half the women reported sexual dysfunction. The dysfunctions were more frequent and more pronounced in individuals treated for rectal cancer than in those treated for cancer of the colon and were worse if the patient had undergone rectal excision surgery or had received radiation treatments, or both⁵⁹. Preoperative radiotherapy, a stoma, and complications during or after surgery were significantly associated with higher sexual dysfunction^{59,64}.

Bowel Dysfunction

Bowel dysfunction was investigated in three reviews^{60,62,63}. Scheer *et al.*⁶³ investigated bowel dysfunctions in 3349 adult rectal cancer patients who underwent AR and reported that 35% experienced incontinence of some kind (solid or liquid fecal incontinence, gas incontinence, failure to differentiate fecal or gas incontinence, urgency, and incomplete evacuation); 14% were affected by fecal

TABLE II General characteristics of the included reviews

Reference	Study type	Details of the included studies						AMSTAR score
		Publications (n)	Characteristics	Population	Sample size (n)	Outcomes measured	Intervention or exposure	
Jeffery <i>et al.</i> , 2007 ⁶¹	Systematic review	8	RCTs	CRC survivors treated surgically	2141	Survival and QOL	Intensive follow-up	9 Benefit in overall survival; no effect on QOL
Jansen <i>et al.</i> , 2010 ⁶⁰	Systematic review	14 (10 studies)	Observational	Long-term CRC survivors (≥5 years after diagnosis)	2187	QOL, comorbidities, distress, and determinants of QOL	CRC incidence and treatment	8 CRC survivors had poorer physical QOL, higher levels of anxiety and depression
Ho <i>et al.</i> , 2011 ⁵⁹	Systematic review	33	Observational (28) RCTs (3) Meta-analysis (1)	Individuals with rectal cancer	6247	Sexual function	Cancer treatment	7 Sexual dysfunctions were frequent with radiation treatment
Scheer <i>et al.</i> , 2011 ⁶³	Systematic review	48	RCTs (12) Cohorts (21) Cross-sectional (15)	Adults with rectal cancer who underwent curative anterior resection	3349	Bowel function	Anterior resection (surgery)	8 Anterior resection is significantly associated with bowel dysfunctions
Cramp and Byron-Daniel, 2012 ⁵⁷	Systematic review	56	All RCTs (only 1 with CRC patients)	Patients or survivors with any type of cancer	102 CRC survivors	Cancer-related fatigue	Aerobics	10 Decreased cancer-related fatigue during and after cancer treatment
Fong <i>et al.</i> , 2012 ⁵⁸	Meta-analysis	34	Only 6 studies involving CRC	Patients or survivors with any type of cancer	579 CRC survivors	Cancer-related fatigue, QOL	Aerobics	10 Clinically significant improvements in physical functioning and QOL
Pachler and Wille-Jørgensen, 2012 ⁶²	Systematic review	26	Observational: cohort (24), case-control (2)	Individuals with cancer of the rectum	3675	QOL	Curative surgeries (abdominoperineal excision vs. anterior resection)	9 No difference in QOL
Traa <i>et al.</i> , 2012 ⁶⁴	Systematic review	82	Cross-sectional (53) Prospective (29) (6 of the latter being RCTs)	All CRC survivors		Sexual function	CRC cancer	9 Of the CRC survivors, 5%–88% experienced sexual dysfunction

RCTs = randomized controlled trials; CRC = colorectal cancer; QOL = quality of life.

TABLE III Limitations of the included reviews

Reference	Important limitations or flaws of the included reviews
Jeffery <i>et al.</i> , 2007 ⁶¹	Intervention in 1 study was similar to the control intervention in another study; one of the included studies was published in 1983, and comparing it with recent studies should be a concern, because treatment and care have greatly evolved in recent years; adjuvant treatment given should be considered as it could prolong survival
Jansen <i>et al.</i> , 2010 ⁶⁰	All included studies were cross-sectional; poor response rate (below 60%), small sample; analyses were explorative and multiple comparisons were not made; comparison with the historical data could imply bias; studies were heterogeneous with respect to instruments used (although valid scales) and analyses
Ho <i>et al.</i> , 2011 ⁵⁹	Use of invalid measurement tools (7 studies); systematic selection bias because some studies excluded some or all sexually inactive patients (14 articles); 13 studies were cross-sectional
Scheer <i>et al.</i> , 2011 ⁶³	Heterogeneity and variability in reporting; 13 cross-sectional studies
Cramp and Byron-Daniel, 2012 ⁵⁷	Heterogeneities in the type of physical activity, intensity, duration, and control intervention (no intervention, wait list, relaxation, general stretching or range of movement exercises, light weights and stretching, <i>tai chi</i> and group psychotherapy); potential for participation bias; only 1 study involved CRC survivors; potential for contamination
Fong <i>et al.</i> , 2012 ⁵⁸	All 6 studies with CRC survivors were RCTs; intensity and duration of the intervention were not consistently reported; heterogeneity in measurement tools; subgroup analyses for CRC survivors not reported; only a results summary provided
Pachler and Wille-Jørgensen, 2012 ⁶²	Follow-up period varied from 14 to 214 months; no baseline measures available for QOL before surgery; missing data and lack of correction for the missing data
Traa <i>et al.</i> , 2012 ⁶⁴	53 Cross-sectional studies; measurement errors (mostly evaluating sexual intercourse or the presence of a sexual dysfunction, or both)

CRC = colorectal cancer; RCTs = randomized controlled trials; QOL = quality of life.

incontinence alone. The other two reviews reported a positive association between the treatment type and incontinence: patients who underwent AR experienced long-term incontinence^{62,63}; those who received preoperative radiation treatment had some kind of incontinence^{60,63}; and those who received short-course radiation therapy had higher rates of long-term incontinence ($p = 0.006$). Furthermore, short-course radiation therapy was a risk factor for liquid and gas incontinence ($p = 0.03$)⁶³.

Physical Activity

Two reviews investigated the effect of physical activity on cancer survivors^{57,58}. Both reported that physical activity provided CRC survivors with clinically important benefits such as reduced body mass index and body weight, an increase in peak oxygen consumption, improved peak power output, lessened cancer-related fatigue during and after cancer therapy, and better QOL^{57,58}. However, the review conducted by Cramp *et al.*⁵⁷ included only one study conducted with CRC survivors ($n = 102$); in the Fong *et al.*⁵⁸ review of thirty-four studies with a mixed group of cancer survivors, six studies included 579 CRC survivors. Although the latter study performed meta-analyses, those analyses did not include a separate analysis of CRC survivors.

DISCUSSION

The overall goal of the present study was to contribute to a consistent evidence-based province-wide approach to survivorship care planning by synthesizing published literature on CRC survivorship and updating the evidentiary base of the SCsPs created in our jurisdiction. To our knowledge, this is the first umbrella review that has investigated

the collective scientific evidence on psychosocial aspects that are important in CRC survivorship care planning. Particularly relevant to the field of synthesis research was the finding that most of the evidentiary base available through high-quality reviews focuses on primary prevention of CRC. Within the limits of the study design, the results of our investigation suggest that CRC survivors

- experience levels of anxiety and distress that are higher than those in the general population,
- more frequently experience sexual and bowel dysfunctions, and
- experience a positive impact on QOL and physical functioning from physical activity.

Our study findings update the evidence and indicate that, with respect to the physical and emotional challenges of CRC survivors, existing SCsPs in our province reflect the evidence available when the SCsPs were issued (Table IV)^{65–68}. However, literature concerning cancer risks specific to CRC survivors is lacking. Although systematic reviews have been considered the “gold standard” in knowledge synthesis^{21,69,70}, our findings suggest the presence of a significant gap in the scientific literature crucial to cancer survivorship care planning and the fact that much remains to be done in the area of synthesis research in survivorship. Clearly, clinician–scientists are drawing from the published evidence in developing SCsPs and are supporting the transition of CRC patients through to survivorship and follow-up in primary care. However, the gap in the literature poses challenges. Clinicians are resorting to the evidence on primary prevention to formulate SCsPs in CRC.

We embarked on this synthesis project with the objective of supporting the production by health care providers of evidence-based information materials to be shared with survivors in our province. Our starting point was the content of the two scps created by our clinician–scientists

for CRC survivors. We aimed to synthesize, within a short period (less than 1 year) and through a systematic review of systematic reviews, the best available evidence to inform a more comprehensive project on scrs. That choice proved to be a challenge, because most of the systematic reviews

TABLE IV Patient outcomes from scientific evidence contained in two provincial colorectal cancer survivorship care plans

Outcome	Survivorship care plan1	Survivorship care plan2
Anxiety	Anxiety is an ongoing physical problem associated with cancer. Learning about the causes of your anxiety is the first step in helping you manage that which makes you feel anxious. Try keeping a diary of moments when your anxiety level increases so that you can identify things that make you anxious.	It is very common to feel some anxiety, apprehension, or nervousness at the end of the treatment. These approaches might be helpful: ■ Emotional and social support from social group, family, and friends ■ Physical activity ■ Spirituality ■ Practical and financial
Fatigue	Fatigue is possibly the most common side effect among people recovering from a diagnosis of cancer or its treatment. Physical activity can help to manage fatigue. Ask for help.	Fatigue is normal and your energy level will eventually return. Many people find that gentle exercises are helpful. Starting off slowly is important. Sometimes resting is as helpful as sleeping.
Weight gain or loss	Some people lose weight without trying after their cancer diagnosis, while others can gain weight. ■ Choose fibre-rich vegetables and fruits, and whole-grain breads and cereals. ■ Limit portions of high-calorie foods.	You might experience appetite changes, gaining or losing weight without trying.
Nutrition and diet	■ Drink 8–10 cups of fluid daily. ■ Eat small portions often. ■ Choose ■ lower fibre fruits and vegetables; ■ grain products that are low in fibre; ■ lower fat choices that are bland and not fried.	Diet plays a significant role in how your bowel functions after treatment. ■ Eating frequent small meals can be a good idea. ■ Limit the intake of very high fibre food ■ A low or low-medium fibre diet is usually your best choice. ■ Consider drinking plenty of non-caffeinated beverages.
Physical activity	Physical activity is an important part of healthy living. It can ■ improve your quality of life. ■ help you to better manage symptoms. ■ reduce anxiety, depression, and fatigue. ■ help with stress and weight management, and improve your body image.	Regular physical activity has been shown to ■ improve physical functioning, ■ reduce cancer related fatigue, ■ improve sleep, ■ reduce feelings of anxiety and depression, and ■ help to maintain a healthy body weight.
Bowel-related side effects	You might experience any one or a combination of loose or frequent bowel movements, incontinence, diarrhea, gas, bloating, or constipation.	Your bowel is likely to change with time. Once your bowel function is settled down to your “new normal,” you can introduce some new food to your diet.
Ostomy	Some people find that the foods they eat can change their output. Some people have trouble with high-fibre foods.	Some foods can cause problems with ostomies. As you experiment with new foods, you will learn what works for you.
Sexual side effects	Problems with erections or ejaculation, or both (men). Problems with pain during sex or vaginal dryness, or both (women).	Many people who have had treatment for their cancer say that they have problems with sexual functioning after treatment. ■ Ongoing fatigue can diminish sexual desire. ■ Nerve damage or scarring in the pelvic area. ■ Women might experience painful intercourse. ■ In men, erectile dysfunction and intensity of orgasm might vary from before treatment to after treatment.
Alcohol	As the amount of alcohol a person drinks increases, the risk of developing cancer increases. To reduce your risk of cancer, limit the amount of alcohol you drink.	There is a debate about the role that alcohol plays in colorectal cancer patients. It is a good idea to talk with your health care provider concerning alcohol intake.
Tobacco use	Tobacco use (including smoking and chewing tobacco) is the single most preventable cause of death, disease, and disability. If you smoke, please ask your doctor for help in quitting.	Smoking is implicated in many cancers. If you smoke, consider quitting, and talk with your health care providers.

that discussed the psychosocial topics included in our provincial SCPS did not yet involve CRC patients and survivors. In fact, the U.S. National Institutes of Health trials registry (<http://ClinicalTrials.gov>), a database of publicly and privately supported clinical studies involving human participants conducted around the world, supports that conclusion. Our recent search of that database using the search terms “colorectal cancer” and “survivor” yielded fifty-seven entries, forty of which were related to psychosocial aspects of survivorship; however, of twelve completed trials, none has yet reported results. Clinical trials are the basis for systematic reviews, and the small number of trials relevant to CRC survivors as the population of interest suggests that little investigation is ongoing. Judging by the number of SCPS available to CRC patients and survivors around the world, the lack of high-quality evidence is, at best, puzzling. We posit that research focusing on survivors—especially clinical trials of interventions that could minimize the known effects of CRC and CRC treatments on QOL—ought to be a priority, because an appreciable proportion of the individuals diagnosed with CRC will live, but with chronic conditions.

In cancer survivors, patient-reported QOL is a frequently measured outcome. Dealing with fear of death, cancer recurrence, and cancer-related challenges has a detrimental effect on QOL for cancer survivors, including those affected by CRC^{71,72}. In the presence of comorbidities, QOL is worse, especially if patients face severe side effects of cancer treatments^{60–62}. Colorectal cancer patients and survivors experience numerous emotional, physical, and functional challenges. It is typical that, in a person facing certain degrees of physical and functional challenges, those challenges can impair psychological adjustment and QOL^{73–75}.

Sexual dysfunction is a frequently observed treatment side effect in CRC survivors, although the severity varies from person to person, by sex, and also by treatment type^{59,64}. Individuals with cancer of the rectum experience higher levels of sexual dysfunction, especially if they undergo certain types of treatment. Sexual dysfunctions were more common in patients who received APE or radiation treatment (or both); bowel dysfunctions were more frequent in patients who received AR. Radiotherapy is known to cause vaginal dryness and narrowing, leading to painful intercourse^{76–78}. Sexual activity requires desire and opportunity, which are related to a variety of factors, such as the individual's psychological state, sexual functioning before the cancer diagnosis, their partner's sexual functioning, and home and cultural influences, among many others⁷⁹. It is therefore necessary to differentiate lack of sexual activity from sexual dysfunction. However, measuring sexual dysfunction in a sufficiently large CRC population, while accounting for various confounding and interacting variables, is a challenging task. A miscellany of interventions to ease bowel dysfunction—such as physical therapy, biofeedback, anal sphincter repair, manipulation of bowel flora with antibiotics, and use of sacral neuromodulation—have been tried, and some seem to deliver benefit, but others do not^{80–83}. However, we could find no reviews that investigated the effectiveness of any such interventions in CRC patients or survivors. Although no

definitive evidence is available at this time, the provision of psycho-education, physical therapies, and counselling for diet and lifestyle changes could potentially help survivors deal with coexisting sexual, urinary, and bowel difficulties. It is clear that there is a serious dearth of reliable scientific syntheses specific to sexual, urinary, and bowel difficulties in CRC survivors. We found only two reviews that investigated the effect of physical activity on CRC survivors, and both found clinically important benefits for survivors with respect to physical functioning and QOL^{57,58}.

To our surprise, we could find no reviews that investigated future cancer risk in CRC patients and survivors, whether as a recurrence or a second primary cancer. However, we did identify twenty-nine reviews (poor-to-moderate quality) that investigated lifestyle factors and their association with CRC incidence in general populations^{25–53}. According to those publications, physical activity^{33,45–47,52}, low body mass index³⁶, fibre-rich diet^{28–30,38,48}, and calcium intake^{31,37,51} lowered the CRC risk; smoking^{32,41,43,49} and consumption of alcohol^{35,40,42,50} and red or processed meats^{25–27,34,39} increased the risk. Although such findings are very important in primary prevention, can that knowledge be applied for secondary prevention in CRC patients and survivors? With the exception of a fibre-rich diet, all the other recommendations to lower cancer risk in the general population were mentioned in the two SCPS from our province.

Even though we observed that certain lifestyles provide protection against CRC in general populations, we could find no reviews that investigated their effect on CRC patient and survivor populations. Nevertheless, SCPS in CRC care often make recommendations related to diet^{84,85}, including the two SCPS from our province. Accordingly, CRC survivors often hear recommendations to consume a diet low in fibre to manage their bowel symptoms. Although controlling bowel symptoms is very important for many, such a recommendation might potentially create undue anxiety, because a low-fibre diet increases the CRC risk in the general population. For CRC survivors, then, it might be important to recommend the other lifestyles factors that are known to lower the cancer risk. Moreover, improvements in physical functioning, QOL, and physical activity might also potentially lower the future risk for cancer in CRC patients and survivors. Alcohol and smoking cessation interventions could also be important in those populations, because such interventions might lower CRC risk and also prevent comorbidities that are associated with alcohol and tobacco use.

Our investigation confirms a serious gap in the literature concerning cancer risk in CRC survivors and also concerning a diet that is functional for CRC patients and survivors. We are therefore highlighting the urgent need for reliable studies that target secondary prevention of cancer for CRC survivors, especially those that explore lifestyle and behavioural factors, including diet. Campbell *et al.*¹⁸ mention that support for patient self-management and use of evidence-based health-promotion interventions were areas of relative weakness when analyzing survivorship models of care used at 8 LIVESTRONG Survivorship Centers of Excellence Network sites in the United States, corroborating our statement.

The present study has some limitations. Although we included moderate- to high-quality systematic reviews or meta-analyses only, we had no control over the studies that were included in those publications. An AMSTAR evaluation assesses only the systematic review, and not the original studies that are included in the review. Quality appraisal of the included primary studies was beyond the scope of our study. Even when quality assessments were performed in the included reviews and meta-analyses, the tools used for the quality assessments varied widely. Some reviews reported heterogeneity for their source studies, and those heterogeneities were not restricted to the measured outcomes alone; they also affected the measuring tools used, follow-up times, the populations studied, and the findings observed. Furthermore, bias was evident in some of the included reviews.

Although we have to recognize the limitations, a major strength of our study is that our umbrella review was conducted very rigorously. Decision-makers are increasingly required to make evidence-informed policy decisions and often have to obtain that evidence within a short time. Within a relatively short period, we were able to collate and highlight where the existing scientific evidence is of superior quality and to provide a snapshot of the events and challenges that are important in CRC survivorship. Using AMSTAR, a recognized quality assessment tool, we were able to assess the quality of the reviews included in the present analysis, giving us confidence about the results reported here.

SUMMARY

The present review combines data from selected high-quality systematic reviews and summarizes the best evidence available to inform clinicians delivering SCPS to people affected by CRC. We posit that the included information is current and reliable, and can potentially help clinicians to make recommendations to people completing treatment for CRC and living with or beyond cancer.

It is possible that well-designed trials focusing on CRC survivorship have been conducted and that the resulting evidence has not yet been synthesized and appraised through systematic reviews. However, our results, together with a search at <http://ClinicalTrials.gov>, suggest that much research remains to be done in the area of CRC survivorship.

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CONFLICT OF INTEREST DISCLOSURES

We have read and understood *Current Oncology's* policy on disclosing conflicts of interest, and we declare that we have none.

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