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**Title: Chapter 24: Colorectal Cancer**

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## **Abstract**

Psychological issues around colorectal cancer (CRC) can emerge from the point CRC is suspected, through treatment, to living with or beyond cancer. A third of patients report high levels of anxiety while undergoing investigations for suspected cancer, and emotional difficulties, particularly anxiety and fear of recurrence, can persist for years following a confirmed diagnosis. Treatments for CRC can result in problems with bowel, urinary or sexual function; and issues with body image following major surgery and/ or the presence of a stoma. Such problems can impact both the patient's social life and ability to work, and result in financial difficulties. Fatigue and difficulty sleeping remain common problems among patients with chronic cancer. Evidence suggests that patients with screen-detected disease experience better quality of life and are more satisfied with their cancer care. Enhancing screening provision and uptake is probably the most effective way of reducing the psychological impact of a CRC diagnosis. However, there are marked differences across countries in screening provision. A substantial proportion of patients living with cancer, and of people cancer-free following curative treatment, report unmet needs around living with anxiety, uncertainty and fear of dying as well as the need for medical support and information. Interventions to reduce unmet needs in cancer patients have had little success to

date, and more effective interventions are required to help CRC patients with the challenges they face before and after a cancer diagnosis.

**Keywords:** Colorectal cancer; Psychology; Psychosocial issues; Quality of life; Cancer Survivors; Needs Assessment

## **Introduction**

Colorectal cancer is the third most common cancer and second most common cause of cancer death worldwide with 1.8 million cases diagnosed, and 881,000 deaths, in 2018. Survival rates are strongly linked to stage at diagnosis, with 90% surviving localised disease (stage I) but only 10% surviving once the disease has spread to distal organs (stage IV). Although global CRC incidence and mortality rates are falling, different patterns are observed between countries. Increases in incidence are seen in countries adopting “Westernised” lifestyles, due to the causal role of lifestyle factors such as obesity and lack of exercise in CRC onset, while declines in mortality are observed in high resource countries, able to offer more effective treatment and early detection initiatives, such as screening programmes.<sup>1</sup>

## **Obtaining a diagnosis**

Psychological issues arise from the moment colorectal cancer is suspected, through treatment, to living with or beyond cancer. Patients with suspected cancer have to undergo medical investigations and attend medical appointments, while facing the threat of a serious illness. Research into distress during the diagnostic phase has shown between 33% to 60% of patients report clinical-levels of anxiety before getting a diagnosis (defined as anxiety high enough to be categorised as an anxiety disorder using psychiatric assessment tools). These levels are equivalent to those observed in patients with a confirmed diagnosis. The majority of studies report anxiety levels remain the same or increase in patients ultimately diagnosed with cancer, while anxiety typically reduces in those with a non-cancer diagnosis.<sup>2</sup> Similar effects have been observed for quality of life (QoL), with patients with suspected cancer reporting the equivalent or poorer QoL as patients with a confirmed diagnosis.<sup>2</sup>

The process of undergoing investigations for suspected cancer presents numerous challenges. In addition to the anxiety associated with waiting for test results, patients with suspected CRC may need to undergo bowel preparations, or have injections, some of which may involve a radioactive ligand (such as for PET-CT), promoting concerns about radiation risk. Scans, such as whole body MRI, are noisy and involve full body immersion into a tube, and can induce anxiety and claustrophobia in a substantial proportion of patients. Particular sectors of the population may find scans more difficult than others. For example, high distress and the presence of comorbidities have both been associated with finding whole-body MRI more challenging, independent of other demographic and clinical variables, among patients with suspected colorectal.<sup>3</sup>

In a retrospective study asking CRC patients in Canada what their specific needs had been during the diagnostic phase, 31.6% reported informational and 20.3% reported emotional needs. While the majority felt their needs had been met at the time, 77.9% reported that they had not been offered help coping with their anxiety, highlighting the need for increased emotional support during the diagnostic phase.<sup>4</sup>

### ***Diagnostic pathways and diagnostic delay***

There are a number of different pathways to a diagnosis of CRC. The most common include screening, planned pathways for the investigation of symptoms of suspected cancer, routine referral for the investigation of symptoms, and emergency presentation (defined as a cancer diagnosis within 28 days of either attending the Accident and Emergency department of a hospital or an emergency hospital admission). Screening and planned-care pathways (e.g. urgent referral to a specialist following cancer “alarm” signals), are designed to diagnose CRC sooner and improve survival rates. The likelihood of experiencing these different pathways, though, varies internationally; for example, organised screening programmes for

colorectal cancer are seen in the majority of European countries but are largely absent in most countries in Central and South America, the Middle East, and Africa. In addition, where offered, uptake rates vary widely from 68.2% in The Netherlands, for instance, to 16% in parts of Canada.<sup>5</sup>

Little work has examined the psychological consequences of the different pathways patients may take to a diagnosis. People who have cancer diagnosed at screening are more likely to have earlier stage disease, requiring simpler treatment, such as surgery alone. A quantitative study in Scotland found that CRC patients diagnosed via fecal occult blood test (FOBT) screening reported better quality of life between 3.5 to 12 years post-diagnosis than people diagnosed following a negative FOBT, or than people who were diagnosed when living in an area that did not offer screening at the time,<sup>6</sup> highlighting superior patient reported outcomes in screen-detected patients.

Perceived quality of care following treatment for CRC in England is also highest among patients diagnosed via screening and worse among patients diagnosed following emergency presentation.<sup>7</sup> While patients diagnosed via emergency presentation have longer surgeries, longer admissions and more readmissions, which may negatively influence their experience of care, they give more negative evaluations of issues such as staff explanations before and after surgery, and of not being involved as much as they wanted to be in treatment decisions.<sup>7</sup> Hence, patient-reported outcomes as well as mortality rates can be improved if more CRC patients are diagnosed via screening.

The main reason for the introduction of diagnostic pathways, such as screening and standardised cancer patient pathways for symptoms of suspected cancer, is to improve cancer outcomes by diagnosing CRC at an earlier stage and reducing the time to treatment. Patients

who wait longer for a diagnosis typically undergo a higher number of medical consultations and investigations. Patients who report a higher number of visits prior to a diagnosis, or a longer period of time between help seeking and confirmation of their diagnosis, report lower satisfaction with their care. For example, patients with anal cancer were more likely to be unsatisfied with their care if they believed there had been a delay in their diagnosis, but satisfaction levels were much lower if patients believed the cause of the delay was due to the medical profession rather than their own fault for failing to seek prompt medical attention.<sup>8</sup>

Some delay in diagnosis can be attributed to cancer site and the non-specific nature of cancer symptoms, making some cancers harder to diagnose than others. However delay can also arise from inefficiencies or errors in care. Increased diagnostic delay has been associated with misdiagnoses, such as attributing the symptoms to a disease other than CRC, failure to examine the patient and negative or false negative results.<sup>9</sup> CRC false negative rates of 8% were reported in a district general hospital in the UK across the 3 modalities of double contrast barium enema, colonoscopy, and computed tomographic colonography, with highest false negative rates observed for barium enema and the lowest for colonoscopy,<sup>10</sup> suggesting that missed cancers are not uncommon. Research into the psychological consequences of having a cancer missed, though, is scant. The study mentioned earlier, comparing psychological outcomes by method of CRC detection in Scotland, found no evidence of adverse psychological outcomes among people who had an “interval” cancer (i.e. a cancer diagnosis following a negative or clear screening outcome), as compared with people diagnosed with CRC in an area not offering screening at the time, on measures of perceived diagnostic delay, quality of life, and depression.<sup>6</sup> However, participants were surveyed between 3.5 and 12 years post-diagnosis. Thus, having a cancer missed had probably not proven fatal, potentially attenuating any adverse effects. The same data showed CRC



survivors who believed their cancer could have been diagnosed sooner, reported greater cancer-related distress, and were more likely to be classified as having post-traumatic stress (PTSD). While part of the relationship between perceived delay and distress was explained by QoL, disease stage at diagnosis and treatment received did not explain the association.<sup>11</sup> The reasons for higher distress among those who believed their cancer could have been diagnosed sooner remain unclear, but could relate to factors associated with delay or the way in which the cancer was diagnosed. Criteria for PTSD (in DSM-5) specify that “Medical incidents that qualify as traumatic events involve sudden, catastrophic events”.<sup>12</sup> In the context of cancer, trauma could arise from diagnostic pathways such as emergency presentation.

Given the obvious distress associated with undergoing investigations for cancer, research has examined whether a more rapid diagnosis is associated with enhanced psychological wellbeing and patient satisfaction with care. However, a more rapid diagnosis means a faster transition from being healthy to being a patient; the diagnosis may be more shocking and hence harder to accept or adjust to. Again, there is little research specifically on patients with suspected colorectal cancer, but in a review of rapid diagnostic pathways (one or two-stop shops), Brocken et al found that anxiety tends to reduce among people with benign outcomes, but is sustained or increased among those diagnosed with cancer.<sup>2</sup> A more rapid diagnosis therefore reduces the duration of anxiety for those with benign outcomes, but did not appear to be either beneficial or harmful for people ultimately diagnosed with cancer.

## **Treatment**

Treatment for colorectal cancer is strongly linked to diagnostic stage. Surgery alone is typically recommended for patients with stage I CRC. Patients with stage III or high risk

stage II colon cancer (e.g. those with large tumours) are offered adjuvant (post-surgical) chemotherapy, while patients with rectal cancer are typically offered neoadjuvant (pre-surgical) radiotherapy with or without chemotherapy in order to reduce tumour size prior to surgery, as well as to reduce the risk of local recurrence. Such treatment for rectal cancer may also be followed by further, adjuvant therapy to stop the emergence of distal disease. Treatment for stage IV disease can still have curative intent with surgical resection of distant metastases, but palliative chemotherapy has also led to reductions in tumour size making surgical resection possible at a later date.

### ***Shared decision making***

Shared decision making is central to patient-centred care, whereby patients take an active role in decisions about their treatment. For patients with either Stage II or III CRC, a key decision is whether to have adjuvant chemotherapy, and if so, which chemotherapy drugs to take. The chemotherapy offered is typically fluorouracil or capecitabine, given on its own or in combination with oxaliplatin. In patients with Stage II CRC, the risk of cancer recurrence is around 20-40% but chemotherapy can only prevent a recurrence in 3-7% of patients.<sup>13</sup> Because some of the side-effects of chemotherapy can be permanent or even life-threatening, the balance of benefits and harms is marginal in this patient group and it is important that the decision be based on patient preferences.

Eighty-five percent of Stage III CRCs relapse within five years. Chemotherapy can prevent relapse in up to 25% of patients and is therefore offered routinely. However the addition of oxaliplatin carries the risk of permanent neuropathy and only offers small additional protection against recurrence, of around 5%.<sup>14</sup> Recent research has shown that reducing the duration of adjuvant chemotherapy from 6 to 3 months can halve the risk of experiencing

permanent neuropathy without adversely affecting survival rates,<sup>14</sup> and that both therapy duration and therapy composition should be discussed and agreed with patients.

### ***Decision support***

Current levels of patient involvement in decision making are suboptimal. For example, in England, patient perceptions of their involvement in cancer treatment decisions are currently assessed via the Cancer Patient Experience Survey (CPES). CPES is conducted by the National Health Service (NHS) England to monitor cancer care and drive forward improvements. Analysis of patient responses to the question: “Were you as involved in decisions about which treatment you would have as you wanted?” showed that rectal and anal cancer patients were less likely to report positive experiences of involvement in treatment decisions than colon cancer patients. People who had had colon cancer reported more positive responses than people with most other cancer types.<sup>15</sup> However, people who responded that there was only one type of treatment suitable for them were excluded from the analysis. People are often unaware that they have a choice of therapy, so the proportion of positive responses to this question may be inflated.

Some rectal cancer patients may be given a choice between a permanent ostomy (a surgically created opening in the body for the discharge of bodily waste) and sphincter-sparing surgery, provided that the probabilities of survival and recurrence are similar. In patients who choose, or need, an ostomy, research has shown that the postoperative period is smoother and emotionally less distressing when it follows adequate preoperative preparation, and when the placement of the stoma (the opening in the abdomen) has taken into account skinfolds and patient preference (e.g., with regard to clothing).<sup>16</sup>

Even when appropriate discussions between patient and provider take place, involving patients in shared decision making presents a number of challenges. While patients with CRC want information about their cancer, particularly in relation to their prognosis and treatment options, there are difficulties in effectively communicating information about likelihoods and potential outcomes of treatment, and adequately supporting patients in making decisions about their treatment.

Patient Decision Aids (PDAs) are specifically designed to assist patients, for example by presenting likelihood information in multiple formats (e.g. as absolute risk, and in both numeric and graphic formats) and including a values-clarification exercise to help patients work out what is more important to them – for example maximising their chances of avoiding a recurrence or accepting a small increased risk of recurrence to avoid long-term treatment side-effects. Although evidence suggests that decision aids can be of benefit in increasing people's knowledge, enhancing people's accuracy about the likelihood of different outcomes and helping people feel both better about the information they receive and clearer about what is important to them, few decision aids have been developed to help people make decisions around colorectal cancer treatment.<sup>17</sup> As people are more likely to survive CRC, the difficulties they face living with the long-term effects of the decisions they have made, and the treatments they have had, become more important.

### **Living with and beyond Colorectal cancer**

Colorectal cancer patients and survivors often report emotional difficulties; problems with bowel, urinary or sexual function; and issues with body image following major surgery, either for resection of disease, the placement of a stoma, or both. Such problems can impact both the patient's social life and ability to work. The likelihood of experiencing such issues is

higher among people diagnosed with later-stage disease and those receiving chemotherapy or radiotherapy.

### *Emotional difficulties and quality of life*

Anxiety, depression and post-traumatic stress disorder are frequently comorbid conditions among cancer survivors. A meta-analysis of the prevalence of anxiety and depression among people two or more years post-diagnosis found that while rates of depression were equivalent to people without cancer (11.6% vs 10%), rates of anxiety were higher (17.9% vs. 13.9%).<sup>18</sup>

Rates of post-traumatic stress disorder are also more common among cancer survivors than people with no history of the disease, although prevalence is typically lower than that of depression and anxiety, with a reported 6.4% point prevalence and lifetime risk of 12.6%.<sup>19</sup>

The proportion of patients reporting emotional difficulties is usually highest shortly after diagnosis and declines over time. However, emotional trajectories vary across patients. Dunn et al conducted a longitudinal, prospective study of distress among CRC patients between 5 months to 5 years post-diagnosis using the Brief Symptom Inventory-18 (a measure combining anxiety, depression and somatisation). They observed four patterns: consistently low distress, observed in 19.4% of patients; medium level distress (going from “case” to “non-case”) in 29.4% of patients; medium increase (going from non-case to case) in 38.5% of patients; and high distress (remaining at case level over time) in 12.5% of patients. The odds of being in one of the medium or high distress trajectories compared with the consistently low distress group were higher for patients with stage III or IV disease, after controlling for age, gender, educational level and social support. While treatment type was a significant predictor in unadjusted analyses, it was not significant in the presence of other variables.<sup>20</sup>

Particular subgroups of the population show greater vulnerability to emotional problems post-diagnosis. A study conducted on CRC patients attending cancer clinics in Scotland found

depression was more likely among women, younger people, and people with higher levels of deprivation.<sup>21</sup>

Higher prevalence of anxiety, depression and symptoms of traumatic stress have also been reported among patients who had adjuvant radiotherapy or chemotherapy compared to those receiving surgery alone, although the impact of disease stage, independent of treatment received, was not examined.<sup>22</sup> Among CRC survivors who had completed treatment for Stage II or Stage III disease, distress was higher among people who reported treatment-related side-effects, such as peripheral neuropathy.

QoL measures capture patients' subjective assessment of physical, functional, psychological and social wellbeing. Different QoL trajectories have also been observed in CRC survivors, followed up from 5 months to 5 years post-diagnosis.<sup>23</sup> Using the Functional Assessment of Cancer Therapy-Colorectal (FACT-C), which has physical, functional, social/family, emotional wellbeing and colorectal cancer specific symptom subscales, Dunn et al found four different QoL trajectories: constant high QoL, observed in 26.2% of patients; constant medium, observed in 47.1%; medium decrease, observed in 7.4% of patients, whereby patients reported a marked decrease in QoL 2 years post-diagnosis, and constant low QoL, reported by 19.2% of patients. Compared to the reference category of consistently high QoL, patients were more likely to be in the QoL trajectories of medium decrease or constant low if they had more advanced disease at diagnosis, although membership was not associated with treatment received.

However, other studies show links between specific treatments or treatment outcomes on QoL. Adverse effects of radiotherapy on long-term bowel and sexual function have been reported in numerous studies, but perceived quality of care at the time of treatment (e.g. lack of treatment-related information, poor control of treatment-related side-effects) also predicts

subsequent QoL in CRC patients, showing that events experienced during treatment can have lasting impact on both patients and their family caregivers.<sup>22</sup>

### *Treatment-related side-effects*

CRC patients undergoing radiotherapy or chemotherapy may experience a number of side-effects, some of which persist once active treatment has finished. A population-based study in Ireland on symptom burden of CRC survivors 1 to 3 years post-diagnosis found the three most commonly reported symptoms were fatigue, insomnia, and flatulence, all of which were reported by over 20% of survivors.<sup>24</sup> This study also found symptoms tended to co-occur, and certain symptoms were more common in patients who had rectal cancer or had a stoma.

Clinically relevant fatigue (defined as worthy of further clinical attention) has been reported in a third of CRC patients attending a regional centre in Scotland, and is more likely among patients who have received radiotherapy or chemotherapy in the preceding two months.<sup>25</sup>

The chemotherapy drug oxaliplatin carries a risk of peripheral neuropathy (PN). Symptoms of PN include insensitivity to cold, numbness, pain, and trouble with balance. Such symptoms have been associated with higher rates of anxiety and depression and can affect people's ability to sleep as well as conduct normal activities of daily living, including work. Estimates of long-term prevalence vary, but one study found that 29% of patients experienced significant neuropathy 3 years after treatment.<sup>14</sup>

Radiotherapy increases the risk of bowel and urinary problems. Bowel problems such as diarrhoea can adversely affect QoL in CRC survivors both in the short and longer-term,<sup>26</sup> resulting in poorer QoL than among people who have never had cancer. However, incontinence following radiotherapy also depends on whether patients have had a stoma or not, which, while reducing faecal incontinence, confers problems of its own.

INSERT BOX 24.1 HERE.

### ***Patients with Ostomies***

Rectal cancer patients concern about a permanent ostomy, frequently supersedes all other consideration (see Box 24.1). Difficulties with self-care are common, with 63 percent of ostomates (people with an ostomy) reporting at least one self-care challenge.<sup>27</sup> Whilst there have been many appliance improvements (e.g. two-piece pouches, stoma plugs, flushable pouches) to help ostomates resume social and physical activities and enhance confidence, the continuing large number of ostomates who adjust poorly highlight the need for strategies to increase self-efficacy and utilising appliance improvements to their full potential.<sup>27</sup>

There is some evidence that female ostomates fare worse than male ostomates. A systematic review found that in all studies included in the analysis, female ostomates showed significantly worse QoL in several domains ( emotional, physical and mental health) compared to male ostomates. Ostomies also have a greater impact on QoL in younger patients compared to older patients.<sup>28</sup> Difficulties with sleep appears to be another concern for ostomy patients, especially for women. The main distress being related to pouch leaks and sleeping positions with some ostomy patients reporting fatigue due to sleep deprivation.

Furthermore, complications due to the ostomy such as; parastomal hernia, parastomal abscess or fistula, retraction, stomal ischemia/necrosis, stoma stenosis, prolapse, bleeding, small or large bowel obstruction and dehydration from high ostomy output, with peristomal leakage and skin breakdown being the most common complications, further decreases ostomates QoL. Surprisingly, some ostomates delay treatment for complications for years, waiting too long or



do not contact a health professional at all. Whilst ostomy complications occur most often within the first five years, the risk of developing a complication remains lifelong.

### ***Body image and sexual functioning***

Sexuality and sexual dysfunction can play an essential role in the psychosocial health of CRC survivors, including those with an ostomy. Di Fabio et al. found that 76% of rectal patients reported sexual dysfunction concerns.<sup>29</sup> Most commonly for males, the presence of an ostomy is associated with higher erectile dysfunction and lower ejaculatory control. Genital pain and lack of lubrication are often reported by woman. Unsurprisingly, reduced intercourse frequency is often the consequence. If unaddressed, these sexual difficulties persist or even worsen and correlate with reduced QoL, including body image, self-esteem, distress and social and physical functioning. There are several known barriers that hinder the management of sexual dysfunction and satisfaction, such as embarrassment, lack of or inadequate information by the care provider before or after surgery, and the timing of interventions.<sup>29</sup> Most treatments for sexual dysfunction have focused on pharmacological options, with varying results. Whilst some treatments are effective in reversing iatrogenic erectile dysfunction, adherence may be an issue. Treatments for women, such as topical testosterone application for low sexual desire, carry potential safety risks and thus are not an option.

There is some evidence that psychological interventions can significantly improve sexual dysfunction in cancer survivors. Gender specific approaches and timing of the intervention appear to be key components for CRC patients. Moreover, body image concerns may contribute to sexual dysfunction and recovery and ought to be addressed. Patients with ostomies are more likely to have negative feelings about their body appearance, which can lead to diminished intimacy and greater isolation. Intimacy concerns are not only related to patients, but ostomies also affect spouses and other partners. Persson et al. found that spouses

of CRC survivors with an ostomy had difficulty with the partner's altered body, reported feeling distant from their partners because of the distress caused by the ostomy surgery, reported difficulty looking at the stoma, and struggled to hide feelings of disgust.<sup>30</sup> Twenty-three percent of CRC survivors with an ostomy indicated that their partner responded negatively during the first sexual experience after ostomy surgery, and 30% stated that their partner reacted with much caution, fearing they would hurt the stoma. Overall, women described their husbands and partners support as central to their psychosocial adjustment to having an ostomy.

### ***Fear of recurrence, and ability to work***

Fear of recurrence (FCR) is a common worry, with a third of CRC survivors reporting concerns a median of 5 years post-diagnosis. One Dutch study found no association between fear of recurrence in CRC survivors and disease stage or treatment received, but greater FCR was associated with higher distress and poorer QoL.<sup>31</sup>

The impact of a cancer diagnosis on financial strain is underexplored, but research has shown that survivors of gastrointestinal cancers are more likely to be unemployed compared with people with no history of cancer (48.8% vs. 33.4%).<sup>32</sup> Reasons for unemployment given include physical limitations and cancer-related symptoms. Inability to work can cause high levels of distress in a substantial proportion of survivors.

### ***Unmet needs***

Improvements in cancer treatment mean more people live with cancer as a "chronic illness" (defined as people with active, advanced or metastatic disease that cannot be cured but that can be managed and is not considered end of life care). Recent research into the symptoms and care needs of this group includes development of a questionnaire (the Chronic Cancer Experiences Questionnaire), assessing difficulties in relation to clinical services, self-

management and self-care, needs for independent living, work, finances and benefits, psychological experiences, support and services, in addition to experiencing ongoing symptoms. This research found the prevalence of cancer-specific symptoms was high, with 80% reporting fatigue and 65.9% trouble sleeping. Approximately one third of patients reported always or often feeling that there were limitations in their physical abilities, social activities and ability to engage in hobbies; a similar proportion reported difficulties planning ahead, and 45.2% reported always or often feeling frustrated at not being able to do what they used to do, and a quarter reported worrying about finances. A third of patients reported often feeling anxiety or worry, and fear of dying, with 71.4% finding uncertainty the most difficult thing to cope with. Poor coordination of care, lack of involvement of their general practitioner or primary care provider and lack of access to support services were also reported. Overall experiences of having chronic cancer were worse among younger patients, patients not currently in a relationship, and those who had had cancer for longer. Despite the increase in studies investigating unmet needs among cancer patients, survivors (people who have had cancer, but are currently cancer-free), and chronic cancer patients, interventions to address these needs have been more limited and the majority have failed to successfully address them.<sup>33</sup>

### **Future Directions**

People diagnosed with CRC face numerous challenges throughout the diagnostic, treatment and post-treatment phases. Emotional difficulties, particularly anxiety and fear of recurrence, can persist for years. Treatments for CRC can result in problems with bowel, urinary or sexual function; and issues with body image following major surgery or the presence of a stoma. Such problems can impact both the patient's social life and ability to work, and result

in financial difficulties. Fatigue and difficulty sleeping remain common problems among patients with chronic cancer.

Evidence, though limited, suggests that better QoL and greater levels of satisfaction with cancer care are reported among patients with screen-detected disease. However, there are marked differences across countries in screening provision.

A substantial proportion of patients living with and beyond cancer report unmet needs around living with anxiety, uncertainty and fear of dying, as well as the need for medical support and information. Interventions to reduce unmet needs in cancer patients have had little success to date.

Future research should aim to minimise the psychological and physical consequences of a CRC diagnosis. Promoting earlier diagnosis, for example, via screening, is one of the best ways of achieving this. More effective interventions are required to help CRC patients in the challenges they face before and after a cancer diagnosis, such as the management of long-term side-effects of cancer-related treatment such as fatigue, and emotional difficulties that may persist for years. Greater patient involvement in decision making around treatments should be encouraged to ensure individuals decide how best to balance quantity with quality of life, rather than maximising survival at any cost.

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## **BOX 24.1 Persistent Ostomy-Specific Concerns and Adaptations are Common in Survivors**

### **Common QOL Issues for Patients with Ostomies**

- Depression
- Chronic anxiety
- Social isolation
- Sexuality
- Body image and appearance
- Self-management of ostomy
  - ◆ Leaks and spillage
  - ◆ Skin problems
  - ◆ Embarrassment due to odour, leakage, and noise
- Dietary concerns
- Constipation
- Comorbidities
- Disrupted sleep due to pouch leaks and sleeping position
- Financial difficulties in paying for ostomy supplies
- Interference with work and social activities
- Physical activities
- Travel difficulties
- Clothing restrictions
- Constant need to adjust to living with an ostomy