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Colorectal Cancer Survivors

How Gastroenterology Nurses Can Help Them Thrive

ABSTRACT

Overall cancer death rates have fallen since a peak in 1991 due to declining death rates for lung, colorectal, breast, and prostate cancers. A "cancer survivor" is defined as anyone with a cancer diagnosis. Their numbers are increasing for several reasons including better screening, earlier detection, and improved treatments. The American Cancer Society's projections for colorectal cancer in 2020 are 147,950 new cases and 53,200 deaths. By 2024, there will be an estimated 1.71 million colorectal cancer survivors (17% of all cancer survivors) and many will experience long-term consequences. These problems may be the result of one or more treatment options: surgical resection, systemic chemotherapy, and radiation therapy. Problems include issues with bowel, ostomy, bladder, sexual health, peripheral neuropathy, and mental health. Colorectal cancer survivors are especially receptive to making lifestyle changes to improve their long-term health. Gastroenterology nurses can utilize evidence-based recommendations for weight management, diet, physical activity, and lifestyle with the goal of preventing recurrence and a second primary cancer and promoting overall long-term health.

verall cancer death rates have fallen since their peak in 1991. This progress was propelled by declining death rates for lung, colorectal, breast, and prostate cancers, the four leading cancers. Colorectal cancer (CRC) is the second leading cause of cancer deaths when men and women are combined; unfortunately, the decline

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has slowed for CRC. The American Cancer Society's (ACS's) projections for 2020 are 147,950 new cases and 53,200 deaths from CRC (Siegel, Miller, & Jemal, 2020).

Cancer Survivors

A "cancer survivor" is defined as anyone with a cancer diagnosis. The numbers of survivors are increasing for several reasons: better screening, earlier detection, and improved treatments. Ranking third for men and women combined, 17% of all cancer survivors had CRC whereas 43% survived prostate cancer and 41% survived breast cancer. Fortunately, the age-adjusted incidence for all cancers combined has decreased over the past 10 years and the number of cancer survivors has continuously grown in the United States (U.S.). This "survivor" statistic is reflective of the increase in the number of new cancer diagnoses due to a growing and aging population and the improved survival as a result of earlier detection and improved treatments. There were approximately 14.5 million survivors in 2014 (the latest year available), and most were diagnosed more than 5 years prior (64%) while some (15%) were diagnosed 20 or more years prior. About half (46%) of those survivors were 70 years or older and 5% were younger than 40 years. It is estimated by

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2024, U.S. cancer survivors will increase to about 19 million (DeSantis et al., 2014).

Colorectal Cancer Survivors

The ACS estimated in 2014 there were more than 1.2 million CRC survivors, mostly older than 60 years (82%; DeSantis et al., 2014). Fortunately, there has been improved uptake of CRC screening since that time (68.8% of adults aged 50–75 years were up to date in 2018; Centers for Disease Control and Prevention, 2019). This screening allows for both CRC prevention through the removal of precancerous polyps and earlier detection and treatment that improve survival.

Between 2009 and 2015, CRC was detected at the localized stage (39%), regional stage (35%), and distant stage (21%) for all races combined (Siegel et al., 2020). Four percent of Stage I and II colon cancers and 18% of Stage I and II rectal cancers are treated with polypectomy alone (DeSantis et al., 2014). The 5-year survival rate (2009–2015) was 90% for localized, 71% for regional, and 14% for distant stage CRC (Siegel et at., 2020). By 2024, there will be an estimated 1.71 million CRC survivors (DeSantis et al., 2014).

Recommendations for Commonly Experienced Consequences of Colorectal Cancer Treatment

Many CRC survivors (hereafter termed "survivors") experience long-term consequences of their CRC treatment. Although they have an overall quality of life (QOL) similar to nonsurvivors, they do have concerns about recurrence (DeSantis et al., 2014). Additionally, some side effects yield a lower physical QOL and contribute to morbidity and mortality. Bowel and ostomy issues, bladder issues, sexual dysfunction, peripheral neuropathy, and mental health problems are among those most often reported. These problems may be the result of one or more treatment options: surgical resection (most common), systemic chemotherapy, and radiation therapy (RT) (Gegechkori, Haines, & Lin, 2017). It is important for the gastroenterology nurse to know about these potential problems, inquire about them, and help patients manage them.

Bowel and Ostomy Issues

About half of all survivors experience chronic diarrhea. Radiation therapy has the potential for adverse effects on the bowels such as urgency, frequency, incontinence, proctitis, and perianal irritation. Lower anterior resections (LARs) and sphincter-saving surgical procedures leave patients especially prone to bowel dysfunction and are in some cases associated with urinary and sexual dysfunction (Gegechkori et al., 2017).

An ostomy is a surgical option for colon cancer (12%) and rectal cancer (29%), and may be temporary

(DeSantis et al., 2014). Ostomy issues include skin irritation, odor, leakage, and emotional and social distress (Gegechkori et al., 2017).

Loperamide (imodium) and diphenoxylate/atropine (lomotil) are antidiarrheal medications commonly used as first-line treatment of RT-induced chronic diarrhea. A menu of cooked vegetables, low fat, and probiotics; or elemental diets (nutritionally complete formulas) may also be helpful. Fecal incontinence can be managed with bulking agents (for a more solid consistency) or antidiarrheal medications. Additionally, biofeedback enhances the musculature of the pelvic floor and abdomen, and another treatment option is surgical modification of the rectum. Patients with persistent symptoms may benefit from a gastroenterology consult. Ostomy therapists can be a great support to patients on ostomy care (skin irritation, odor, gas, appliances, and equipment). Support groups can also help patients adjust and live with an ostomy (El-Shami et al., 2015).

Bladder Issues

About one third of all survivors have long-term bladder incontinence or difficulty emptying the bladder, and about three of four survivors experience urgency or urge- and stress-related incontinence. Radiation therapy in particular may have the following adverse effects on the bladder: difficulties with voiding, bladder emptying, overflow incontinence, and diminished sensation of fullness. Sacral splanchnic nerve damage can result in detrusor denervation and decreased bladder sensitivity (Gegechkori et al., 2017).

Urodynamic studies can help diagnose the problem of urinary retention postsurgery. Patients with hypocontracting bladders may need to perform selfcatheterization. Stress incontinence may improve with Kegel exercises, provided innervation remains intact. Fluid limits, particularly for caffeinated beverages, may also help. Medications for stress incontinence include anticholinergics, whereas urge and mixed incontinence may be controlled with antimuscarinics. Acidic foods such as citrus, caffeine, and tomatoes are known to irritate the bladder and can exacerbate urgency and frequency, so should be avoided. Hematuria post-RT can occur, but other causes should be eliminated by cystoscopy (El-Shami et al., 2015).

Sexual Dysfunction

More than one of three CRC survivors experience treatment-related sexual dysfunction and two of three survivors experience lack of libido, erectile dysfunction (ED) or ejaculatory problems, vaginal dryness, or painful sex. Some risk factors for sexual dysfunction are RT, nerve damage, ostomy or leakage from an ostomy site, and blood loss (Gegechkori et al., 2017). Surgical procedures can damage the sacral plexus and result in ED or painful sex.

Men can have testosterone levels evaluated and get testosterone replacement, if needed. Oral phosphodiesterase-5 inhibitors are effective for men experiencing ED. Vaginal moisturizers and lubricants are helpful for women who experience vaginal dryness or painful sex. Men and women can also benefit from sexual health programs or counseling (El-Shami et al., 2015).

Peripheral Neuropathy

Chemotherapy with oxaliplatin carries a risk of peripheral neuropathy of most large sensory nerves. These paresthesias are partially reversible; however, less than 40% of survivors experience a complete recovery (Gegechkori et al., 2017).

Other neuropathic pain has been treated with gabapentin, tricyclic antidepressants, baclofen, and ketamine, so these options may be offered. Duloxetine may reduce the pain, tingling, and numbness. Physical therapy, occupational therapy, or rehabilitation medicine may also be helpful (El-Shami et al., 2015).

Mental Health

Cancer recurrence is a common worry among survivors. About 50% of survivors do have a recurrence within 3 years of the initial surgery plus they are at an increased risk of another primary CRC at other sites, particularly in the digestive system (DeSantis et al., 2014). Survivors can experience cognitive impairment (36%-52%)including the domains of processing speed, verbal memory, attention, and working memory. Chemotherapy may exacerbate this impairment, but the conditions of most survivors will improve once the treatment is complete (Gegechkori et al., 2017). Other mental health concerns include distress, anxiety, depression, and alterations in body image (El-Shami et al., 2015).

The Distress Thermometer (a 10-point, visual analog scale), with 0 indicating no distress to 10 indicating extreme distress, is a quick screen for mental distress. A score of 4 or higher indicates a need for further evaluation. Similarly, there are reliable tools for the evaluation of anxiety and depression, which are common in survivors. Poor emotional well-being has been linked to reduced survival, so these patients should be referred to community resources and mental health professionals (El-Shami et al., 2015).

Other Issues

Chronic pain is problematic for one of four survivors and may impede recovery or rehabilitation. Survivors may also have genetic, reproductive, social, employment, and financial concerns (El-Shami et al., 2015). Radiation therapy may increase fracture risk, particularly of the pelvis. Chemotherapy also causes multiple issues for survivors. The risk of long-term effects of chemotherapy depends upon the type, duration, dose, and age of the patient. Chemotherapy with 5-fluorouracil (5FU) is associated with cardiotoxicity in up to 68% of survivors. The symptoms include arrhythmias, chest pain, myocardial infarction, heart failure, cardiogenic shock, and death. This cardiotoxicity is especially associated with a history of coronary artery disease or mediastinal RT (Gegechkori et al., 2017).

Goals of Colorectal Cancer Survivorship Care

The cancer continuum has a minimum of three phases of survival: (1) from the initial diagnosis until its treatment is complete; (2) the treatment-to-survival transition; and (3) long-term survival. The U.S. cancer success story has more survivors than ever. But in response to this good news, primary care providers (PCPs), in partnership with oncologists, must identify and manage survivors' health risks and facilitate QOL with consensus-based guidelines for treatment and followup care. This care includes (1) identification and management of physical and psychosocial treatment effects (both long term and late); (2) screening for CRC recurrence and other primary cancers; (3) health promotion; and (4) enhanced communication between the primary and oncology care teams. The goal is to optimize the care provided to improve survivors' overall health and QOL through these three phases of survival (El-Shami et al., 2015).

Surveillance

Surveillance for recurrent CRC or a new primary cancer should be initiated for all survivors except those with severe comorbidities that make them poor candidates for surgery or systemic therapies. Stage I survivors need a colonoscopy 1 year after resection; if there are no abnormal findings, then repeat at 3 and 5 years. Adenomatous polyps, however, prompt more frequent follow-ups (based upon the pathology). The PCP should use the same screening recommendations for new primary cancers that are used on the general population (El-Shami et al., 2015). Recommended follow up per stage includes the following (El-Shami et al., 2015):

- A history and physical (H & P) allows the PCP to identify symptoms, provide counseling, and coordinate necessary care. Stage II and III survivors need an H & P every 3–6 months during the first 2 years, followed by every 6 months during Years 3, 4, and 5. Thereafter, the H & P should be done yearly.
- Carcinoembryonic antigen (CEA) testing after T2 (tumors that have grown into the muscularis propria) or greater lesions should be done every 3–6 months

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during the first 2 years. Thereafter, every 6 months for Years 3, 4, and 5, after which time CEA testing is no longer necessary.

- Stage III survivors need chest, abdomen, and pelvis computed tomographic (CT) scans annually for up to 5 years. Thereafter, CT scans are not recommended. Positron emission tomography/computed tomography (PET/CT) is not recommended.
- Stage IV survivors without evidence of post-treatment disease need chest, abdomen, and pelvis CT scans every 3–6 months during the first 2 years, followed by every 6–12 months during Years 3, 4, and 5. Thereafter, these CT scans are not recommended. PET/CT is not recommended.
- Rectal cancer survivors who had an LAR need a proctoscopy every 6 months for 5 years. They also need an endoscopic rectal anastomosis evaluation for recurrence (the timing of which is uncertain).

Survivors who have a greater risk of a second primary cancer because of genetic predisposition need a more intensive screening regimen. Female survivors with Lynch syndrome (or hereditary non-polyposis colorectal cancer [HNPCC]) need endometrial sampling and transvaginal ultrasonography (TVUS) annually. Starting at 35 years of age, an annual endometrial biopsy is needed because of a lifetime risk of endometrial cancer of 27%–71%. An additional endometrial biopsy is needed if these women have irregular or postmenopausal vaginal bleeding. Their lifetime risk of ovarian cancer is 3%–14%, so at least, annually, a rectovaginal examination, CA-125, and TVUS should be done. A bilateral oophorectomy is recommended at 35 years of age (El-Shami et al., 2015).

Primary Care and Oncology Providers: A Partnership for Winning the Colorectal Cancer Battle

Improved screening adherence allows for finding cancers at an earlier, more treatable stage. Improved cancer treatments have led to the increased numbers of survivors in the U.S. Their QOL, however, may be affected by long-term and latent side effects. Primary care and oncology providers need to ask patients targeted questions to screen for these side effects and assist patients to manage them (El-Shami et al., 2015).

Lifestyle Strategies for Colorectal Cancer Survivors

Survivors are especially receptive to making lifestyle changes to improve their long-term health, which makes a wonderful teaching opportunity for gastroenterology nurses. The ACS provides evidence-based recommendations for weight management, diet, and physical activity with the goal of preventing CRC recurrence and a second primary cancer (Rock et al., 2012). The Institute of Medicine considers these interventions a necessary extension of cancer treatment through tertiary prevention (limiting the sequelae of a condition) that promotes overall long-term health (Demark-Wahnefried et al., 2015).

Weight Management

Weight loss is one symptom of cancer, so many patients go into treatment with cachexia (body wasting). Many patients experience nausea and vomiting with chemotherapy, which may also alter taste and smell or cause mouth sores that make eating difficult. Early satiety further compromises nutritional status. Conversely, CRC is an obesity-related cancer and the current obesity epidemic means many patients may enter treatment overweight or obese and can even gain weight during treatment (Rock et al., 2012). There are 13 cancers associated with overweight and obesity (meningioma, esophagus, multiple myeloma, kidney, endometrium, ovary, thyroid, breast, liver, gallbladder, stomach, and pancreas in addition to CRC) (National Cancer Institute at the National Institute of Health, 2017). Therefore, patients with these cancers are especially at risk of another primary cancer (Demark-Wahnefried et al., 2015).

The ACS recommendation is to achieve and maintain a healthy weight. The association between body weight and CRC mortality is "J" shaped (not linear), so the rank of mortality is as follows: patients with the highest weights (obese; body mass index [BMI] \geq 30 kg/m²) have the highest mortality, followed by those who are either normal or underweight (BMI <25 kg/m²), whereas overweight (BMI = 25–29.9 kg/m²) patients have the lowest mortality. Obesity increases the risks associated with cancer treatments and can also lead to complications of impaired wound healing, post-surgical infections, lymphedema, and comorbidities, which may contribute to a further decline in health (Demark-Wahnefried et al., 2015).

Being overweight is associated with an increased risk of recurrence, and reduced disease-free and overall survival. Survivors, regardless of weight at the time of diagnosis, experience health benefits when a healthy weight is maintained. Weight loss should be achieved by a low-calorie-density nutritious diet accompanied by physical activity. Water- and fiber-rich fruits and vegetables (five servings per day), nuts, seeds, legumes, whole grains, poultry, fish, limited red meats, low fat, and no sugar-added foods and beverages of limited portion sizes should be emphasized along with increased physical activity. More severely obese survivors may benefit from weight loss programs or pharmacological or surgical means of weight loss (Rock et al., 2012).

Physical Activity

The ACS recommends CRC survivors avoid inactivity and engage in physical activity. Reduced activity was found to be associated with greater fatigue, reduced role function, lower physical function, and a lower QOL (Viscuse et al., 2017). There is evidence of an inverse relationship between physical activity and mortality after a CRC diagnosis. In fact, the most active CRC survivors had a lower risk of death not only from CRC but also from other causes, particularly among those survivors who *increased* their activity after the diagnosis (Demark-Wahnefried et al., 2015).

The activity goal is at least 150 minutes per week including strength training twice weekly (Demark-Wahnefried et al., 2015). Walking is an easy and readily available exercise option. Every increment of 10 minutes counts toward that weekly 150-minute goal; survivors can add multiple shorter sessions throughout the day. More intense exercises of longer duration may have additional benefits. A reasonable goal is to be as active as possible and minimize sedentary behavior.

Survivors who do need to sit can add small, frequent breaks of standing, stretching, or brief slow walks. Tai chi is a gentle exercise in which survivors may engage if more vigorous exercise is not possible (Van Blarigan & Meyerhardt, 2015). Older survivors or those with issues such as osteoporosis, bone metastases, peripheral neuropathy, weakness, loss of balance, or arthritis should have assistance to prevent falls and injuries. Caregiver assistance or physical therapy can be helpful for this population. A stationary reclining bicycle may be an exercise option they can manage. Survivors confined to bed benefit from physical therapy to maintain range of motion and strength and reduce depression and fatigue. Support groups, telehealth counseling, and motivational interviewing may help survivors (Rock et al., 2012).

Nutritional Support

Nutrition can be a special challenge for CRC survivors, and referral to a registered dietitian, preferably a certified specialist in oncology, is helpful to meet these challenges. Multiple goals for survivors include to resolve or prevent nutritional deficits and their adverse effects, preserve muscle mass, maintain a healthy weight, and improve QOL (Rock et al., 2012).

Some common nutritional support recommendations include smaller more frequent meals to promote intake among survivors with early satiety or anorexia. Beverages should be included *between* meals to promote hydration. Fortified, nutrient-dense foods or beverages assist with energy and nutrient intake. Some survivors benefit from appetite stimulants, tube feedings, or parenteral nutrition. Supplementation with vitamins and minerals is controversial; many experts recommend against this practice except to treat a deficiency or support a specific health issue such as macular degeneration or osteoporosis. Supplementation with greater than 100% of the Daily Value should be avoided (Rock et al., 2012).

Alcohol and Tobacco Use

Alcohol is associated with a risk for primary cancers of the mouth, pharynx, larynx, esophagus, liver, colon, and breast (Shield, Parry, & Rehm, 2014). A recent study purports that there is no safe amount of alcohol because there are massive associated health risks. The risk of cancer and mortality rises with consumption levels, and the level of consumption that minimizes these risks is zero (Global Burden of Disease 2016 Alcohol Collaborators, 2018). For these reasons, the 2020 American Cancer Society Guideline for Diet and Physical Activity for Cancer Prevention added the recommendation to not to drink alcohol. Men who do drink alcohol should have a limit of two drinks per day and women 1 drink per day (defined as 5 oz of wine, 12 oz of beer, or 1.5 oz of 80-proof alcohol, which is about 14 g of ethanol; Rock et al., 2020). Small amounts of alcohol (such as in mouthwashes) can be irritating to survivors with mucositis (Rock et al., 2012). The Alcohol Use Disorder Identification Test (AUDIT) developed by the World Health Organization is a quick 10-item screening tool gastroenterology nurses and providers can use to evaluate consumption, behaviors, and problems associated with alcohol use (National Institute of Health, n.d.). Survivors with alcohol use disorder can be referred to support groups and local treatment programs.

Tobacco use is associated with oral, nasal, pharyngeal, throat, esophagus, stomach, pancreatic, colon, liver, kidney, bladder, ovary, uterus, and cervix cancers and myeloid leukemia (Cancer Council, 2016). Tobacco use is the most preventable cause of disease and premature death in the U.S., and gastroenterology nurses and providers need to make tobacco cessation a top priority. One time-efficient and yet effective strategy is to use the "5 A's of Smoking Cessation" (Ask, Advise, Assess, Assist, and Arrange), which are used to determine a tobacco user's readiness to quit. The steps are to (1) ask about tobacco use at every visit; (2) advise the patient to stop using tobacco; (3) assess whether the patient is willing to try quitting at this time; (4) assist the willing patient with counseling and/or pharmacotherapeutics and establishing a quit date; and (5)arrange a follow-up within 1 week of the quit date (Agency for Healthcare Research and Quality, 2012). The goal is that with consistent use at every patient encounter, the tobacco user will move one step closer toward cessation.

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Mental Health

Fear of recurrence, anxiety, depression, and stress are long-term and late sequelae of cancer and its treatment that CRC survivors experience. The cost of treatment or inability to work may lead to financial strain that exacerbates these mental health conditions. The combination of physical and mental strain affects QOL (Viscuse et al., 2017).

Gastroenterology nurses can recommend exercise to reduce this psychosocial distress, depression, and fatigue because exercise improves self-esteem and QOL (Rock et al., 2012). Many survivors have utilized massage therapy for pain relief and to assist with insomnia, anxiety, and fatigue, depression. Gastroenterology nurses can recommend massage along with other options such as meditation, yoga, and discussions about stress and coping. The use of Chinese medicine such as acupuncture, moxibustion, and acupressure has also been supported by research (Viscuse et al., 2017).

Conclusion

The gastroenterology nurse is strategically positioned to give anticipatory guidance to the soon-to-be estimated 1.71 million CRC survivors. Although these survivors have an overall QOL similar to nonsurvivors, they do have concerns about recurrence and some side effects that yield a lower physical QOL and contribute to morbidity and mortality (DeSantis et al., 2014). Prime among these issues include the bowel and ostomy problems of chronic diarrhea (most frequent), urgency, frequency, incontinence, proctitis, or perianal irritation. Bladder issues of incontinence or difficulty emptying the bladder and urgency or urge- and stress-related incontinence are common. Sexual dysfunction symptoms may include lack of libido, ED or ejaculatory problems, vaginal dryness, or painful sex. Chemotherapy-related peripheral neuropathy may or may not be reversible and most often affects large sensory nerves. Chronic pain can impair recovery or rehabilitation (Gegechkori et al., 2017). Mental health problems affect QOL and can include distress, anxiety, depression, and alterations in body image (El-Shami et al., 2015).

The first step in resolving any of these problems is to identify they exist. The gastroenterology nurse needs to anticipate these problems, assess them, and coordinate interventions to help patients manage them. Gastroenterology nurses care for survivors in all areas of the care continuum: (1) from the initial diagnosis until its treatment is complete; (2) the treatment-tosurvival transition; and (3) long-term survival (El-Shami et al., 2015). The goal is to optimize the care provided to improve survivors' overall health and QOL. These patients have special needs for nutritional support, weight management, physical activity, and possibly smoking cessation (Rock et al., 2020), all of which enhance survival. Gastroenterology nurses can also help patients navigate alternative therapies to aid with symptom reduction. The numbers of CRC survivors are anticipated to grow and so, too, will the demand for survivor support. Gastroenterology nurses' knowledge of these evidence-based interventions will help CRC survivors maximize their QOL plus reduce their risks of recurrence and a second primary cancer.

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