

# Lack of Support and Information Regarding Long-Term Negative Effects in Survivors of Rectal Cancer

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**Background:** Rectal cancer is a common cancer. Curative treatment frequently includes surgery, radiation, and chemotherapy, all of which can result in long-term adverse effects.

**Objectives:** This descriptive, hypothesis-generating study sought to obtain input from survivors of rectal cancer regarding key features of their long-term experience.

**Methods:** The authors administered a 12-question, Internet-based survey to self-identified rectal cancer survivors to assess (a) how neuropathy, fatigue, trouble with ostomy or bowel movements, and trouble with sexual function affect daily life and (b) whether knowing about these symptoms a priori would have changed their treatment decisions. Responses are presented descriptively. Qualitative analysis assessed themes reported in response to an open-ended question.

**Findings:** Responses from 116 survivors of rectal cancer, 55 of whom provided open-ended responses, were obtained. Respondents were predominantly young and several years from treatment. They reported that their lives were affected “a lot” by bowel or ostomy trouble, trouble with sexual function, fatigue, and nerve toxicity. Survivors reported that knowing whether symptoms would affect their lives “a lot” would have changed their treatment decisions with a priori knowledge of these lasting effects. Key qualitative themes were the lack of information about and support for negative effects.

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Colorectal cancer is second only to lung cancer in annual incidence in the United States, affecting 1 in 20 Americans at some point in their lives (American Cancer Society, 2015). Cure rates for colorectal cancer continue to rise (Edwards et al., 2010), and colorectal cancer survivors now comprise 8%–9% of the estimated 14.5 million cancer survivors living in the United States (DeSantis et al., 2014). Unfortunately, the treatments used to cure colorectal cancer, including surgery, chemotherapy, and radiation therapy, carry substantial risk of long-term sequelae.

Colorectal cancer treatment undoubtedly results in lasting effects on health-related quality of life and symptom burden

among survivors. Colorectal cancer survivors have been reported to have lower health-related quality of life for as many as 10 years after completing treatment (Jansen, Herrmann, et al., 2011; Jansen, Hoffmeister, et al., 2011). However, other studies have reported that only a minority of patients have lasting detrimental effects from treatment (Ramsey, Berry, Moinpour, Giedzinska, & Andersen, 2002; Rauch, Miny, Conroy, Neyton, & Guillemin, 2004; Sapp et al., 2003; Zucca, Boyes, Linden, & Girgis, 2012). When present, these detrimental effects include disease-specific issues, such as difficulty with ostomy and bowel function and sexual dysfunction. They also encompass nonspecific adverse sequelae common to all cancer survivors, such as