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Sources of distress among patients undergoing surgery for colorectal cancer: a qualitative study

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ABSTRACT

Background: Distress is common among cancer and surgical patients and can lead to worse outcomes if untreated. The objective of this study was to explore sources of distress among colorectal cancer patients undergoing surgery.

Materials and methods: This was a qualitative study using in-depth, semistructured, one-on-one interviews in an academic setting. Patients were recruited if they had a pathologically confirmed diagnosis of colon or rectal cancer. Purposive sampling was used to recruit patients who were about to undergo (preoperative), or had recently undergone (post-operative), curative resection for colorectal cancer.

Results: All participants ($n = 24$) reported experiencing distress during treatment. Participants identified sources of distress preoperatively (negative emotional reaction to diagnosis, distress from preconception of cancer diagnosis, and distress interacting with healthcare system). Sources of distress during in-hospital recovery included negative emotional reaction to having a surgery and negative emotions experienced in the hospital. Postoperative sources of distress included mismatch of expectations and experience of recovery, dealing with distressing physical symptoms and complications after surgery, and distress worrying about recurrence. Participants identified other sources of distress that were not time-specific (distress related to social support network, from disruption of life, and worrying about death).

Conclusions: Our results highlight a potential role for a comprehensive screening program to identify which patients require assistance with addressing sources of distress during the surgical experience. Understanding how sources of distress may vary by time will help us tailor interventions at different time points of the surgical experience.

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Introduction

An estimated one-third of patients with cancer will experience clinically significant distress, such as anxiety or depression that is associated with their diagnosis and treatment. The presence of anxiety and depression has been shown to negatively impact health outcomes and quality of life in patients with cancer. Distress extends along a continuum from normal feelings of sadness and fear to disabling components of depression, anxiety, and existential crisis. Distress is known to be multifactorial and may interfere with a patient's ability to cope with treatment.¹⁻⁵

As a result, the National Comprehensive Cancer Network⁶ and the American College of Surgeons Commission on Cancer^{7,8} recommend screening all new cancer patients for distress.

In addition, it is known that among all surgical patients, anxiety and depression are prevalent. In fact, in one study, over half the patients undergoing surgery screened positive for depression and one-third had anxiety.⁹ Colorectal surgery patients in particular are at a unique risk because of the emotional stress of the possibility of having an ostomy and the changes in which surgery affects gastrointestinal function. One study found that 35%-71% of preoperative patients preparing for colorectal resection with stoma had symptoms of anxiety or depression.¹⁰ The presence of anxiety and depression has been shown to impact surgical outcomes negatively among patients with cancer.¹¹⁻¹³ Beyond the in-hospital recovery, untreated preoperative distress among colorectal cancer patients is associated with worse quality of life and well-being 2 y after surgery.¹⁴

Currently we have limited understanding of the sources of distress on colorectal cancer patients undergoing surgery. The objective of this study was to explore sources of distress among patients with colorectal cancer before surgery, during the in-hospital recovery, and postdischarge after surgery.

Materials and methods

Study design and recruitment

Qualitative methodology was chosen to explore this research question because this methodology is particularly useful when you are trying to understand the depth and breadth of a problem or trying to generate hypothesis about ways to impact it.¹⁵ Qualitative research approaches have been demonstrated to be an important adjunct tool to quantitative research in surgery.^{16,17} In the present study, patients were recruited from a colorectal surgery clinic at a single academic institution (NewYork-Presbyterian/Weill Cornell Medical Center). Patients were included for analysis if they had pathology-confirmed diagnosis of colorectal cancer and had recently undergone (postoperative) or were about to undergo (preoperative) curative resection for colorectal cancer. Existing support systems beyond the colorectal surgeon at our institution include a dedicated ostomy nursing team, office-based nurse practitioners, free referral to registered dietitians, and availability of social worker when needed.

Furthermore, our institution has adopted an enhanced recovery after surgery protocol, and all patients undergo standard education about the perioperative process that did not change during the study period. Of note, this process does not include any formal screening program for distress.

We used a purposive sampling strategy¹⁸ to recruit patients using the aforementioned inclusion criteria with emphasis on including preoperative and postoperative patients to ascertain their perceptions of sources of distress, if any, throughout the surgical experience. Based on prior literature and guidance from experts in qualitative methodology, preoperative patients were included because postoperative patients may not accurately recall their preoperative experiences and may not be able to reliably report sources of distress before surgery.^{19,20} Postoperative patients were included because preoperative patients can only talk about their expectations of the surgery, not their actual experiences. The surgical experience and postoperative recovery might cause distress, especially if a patient develops a complication. This would not be captured if only preoperative patients were recruited. Postoperative patients were recruited no less than 2 wk after discharge so that the interview could probe for sources of distress related to the discharge process and transition to home. Postoperative patients were recruited up until 6 mo after surgery to ensure capture of potential sources of distress related to recovery at home. Interviews were not conducted beyond 6 mo after surgery, so the memory of the surgical process was not too old. Interviews were continued until no new answers were heard during interviews, termed "data saturation".^{21,22}

Data collection

Once patients were recruited and informed consent was obtained (Institutional Review Board protocol #1508016507), patients were given a series of validated patient-reported surveys to capture baseline levels of functional independence (Katz Activities of Daily Living²³), symptoms of anxiety and depression (Hospital Anxiety and Depression Scale [HADS]²⁴), quality of life (Euroqol-5 dimension-5 level²⁵), and satisfaction with surgical care if they had undergone surgery (the Consumer Assessment of Healthcare Providers and Systems Surgical Care Survey²⁶). Additional information was collected from the medical record including the Charlson Comorbidity Index,²⁷ clinical or pathologic stage, treatment with chemotherapy or radiation, length of stay, complications, and readmissions.

Semistructured, open-ended, one-on-one interviews were conducted between a researcher trained in qualitative interviewing (J.S.A.) and the patient. Training in qualitative research was obtained during coursework for a Master of Science degree. Preoperative patients were asked about their emotions experienced before surgery as well as their expectations of surgery and recovery. Postoperative patients were asked about their emotions experienced before surgery, during the in-hospital recovery, and after discharge. Specific sources of distress were then probed for each participant. All

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