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## Quality of Life, Symptoms, and Self-Management Strategies After Gastroesophageal Cancer Surgery

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### Keywords

Esophageal cancer; gastric cancer; quality of life; symptoms; dietary adjustments; self-management

### To the Editor:

The most common and effective treatment strategy for gastroesophageal cancer is surgery. Surgical procedures (esophagectomy, gastrectomy) are invasive and complex, and risk for postoperative complications is high (up to 40%).<sup>1</sup> Postoperative recovery is slow, with impairments in quality of life (QOL) that can persist ten years after surgery.<sup>2</sup> Nutritional symptoms are common (nausea, vomiting, early satiety, diarrhea, pain), and often result in severe malnutrition.<sup>3</sup> These symptoms and associated eating problems are often a major source of anxiety for patients postoperatively.<sup>4</sup> Few studies have attempted to understand the strategies that gastroesophageal cancer patients use to manage nutritional symptoms and eating problems. In this study, we evaluated QOL, symptoms, and self-management strategies following gastroesophageal cancer surgery.

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## Methods

This cross-sectional study was conducted at an NCI-designated comprehensive cancer center and approved by the Institutional Review Board (IRB). Using existing institutional surgery datasets from 2014 to 2015, we identified eligible participants using the following criteria: 1) had an esophagectomy or gastrectomy, 2) were 6–12 months post-resection, and 3) were 21 years of age and older. A packet containing an invitation letter for study participation and informed consent was mailed to eligible participants. Research staff contacted participants one week after packet mailing. Following informed consent, surveys were completed verbally or by postage-paid mailing based on patient preference.

All participants completed the following validated measures: the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC-QLQ30), the EORTC-Oesophageal or Gastric Cancer Module (EORTC-QLQ-OES18 or STO22), and dietary patterns and behavioral adjustments questions from the City of Hope-Quality of Life tool (COH-QOL). The EORTC-QLQ is a well-validated 30-item instrument for QOL assessment, with subscales/items for function, global health, general symptoms (fatigue, pain, nausea & vomiting), and financial toxicity.<sup>5</sup> The EORTC-QLQ-OES18 is an 18-item measure of esophageal cancer-specific symptoms and emotional sequelae.<sup>6</sup> The EORTC-QLQ-STO22 is a 22-item measure for gastric cancer-specific symptoms and emotional well-being.<sup>7</sup> Finally, we used questions from the validated 43-item COH-QOL tool to assess diet and behavioral adjustments. These included time to comfort with diet, number of meals/snacks/drinks per day, and number/types of behavioral/lifestyle adjustments to control symptoms and enhance nutritional intake.<sup>8</sup> Descriptive statistics (means for normally-distributed continuous data, medians for non-normally distributed continuous data, and proportions for categorical data) were summarized for sociodemographics, clinical, disease, QOL, symptoms, and self-management data.

## Results

The overall response rate to the survey was 67% (31 complete/46 eligible), with 11 esophagectomy and 20 gastrectomy participants enrolled. Mean age was 62 (range 42–87), and most participants were male (64.5%). Disease stage distribution are as follows: 11 stage I (35.5%), 2 stage II (6.4%), 15 stage III (48.4%), and 3 stage IV gastric cancer patients (9.7%). Fourteen participants (45.2%) received neoadjuvant chemotherapy/chemoradiation (ECF, carboplatin/paclitaxel), and 16 (51.6%) were treated adjuvantly (FOLFOX, radiation). Most participants (26; 83.8%) reported having 2 or more preoperative comorbidities. Thirty-day postoperative complication rate was 35.4%; 5 participants (16.1%) were readmitted at 90 days after surgery.

QOL and symptom scores (general and disease-specific) are presented in Table 1. Global health status scores were moderate ( $62.9 \pm 12.0$  esophagectomy,  $64.6 \pm 23.9$  gastrectomy). For QOL subscales, social functioning score was the lowest for esophagectomy patients ( $62.1 \pm 29.9$ ), while role functioning was the lowest for gastrectomy patients ( $73.3 \pm 32.2$ ). For general symptoms, fatigue was the most severe for esophagectomy patients ( $45.4 \pm 23.5$ ), followed by appetite loss, insomnia, and dyspnea. For gastrectomy patients, financial difficulties was the most severe ( $40.0 \pm 44.1$ ), followed by fatigue, appetite loss, and

insomnia. For disease-specific symptoms, eating restrictions was a major problem for all patients. Trouble with cough, taste, and reflux were also problematic for esophagectomy patients. Gastrectomy patients reported problems with body image, dry mouth, and pain.

For diet adjustments, most participants felt comfortable with eating between 1–12 months after surgery, but a subset of participants (5; 16.1%) reported never achieving comfort with eating at the time of survey. Most participants ate an average of 3–4 meals per day (range 2–7), with an average of 2 snacks per day (range 0–5). The number of behavioral and lifestyle changes since surgery ranged from 2 to 9. A variety of behavioral and lifestyle self-management strategies were reported for symptom management. Participants chewed food completely, ate smaller meals throughout the day, and controlled their meal portions to manage symptoms and eating problems. Other reported strategies included staying/sitting upright after eating, keeping upper body/head raised when sleeping, and planning social activities around eating.

### Comment

Eating problems and associated symptoms are among the most common complications after gastroesophageal cancer surgery. Importantly, nutritional symptoms and eating problems are modifiable, underscoring the need to identify effective approaches that contribute to symptom relief. Our findings confirm evidence from previous studies, which also found lower social/role functioning and similar persistent symptoms (fatigue, appetite loss) six months after surgery.<sup>4</sup> Although gastroesophageal cancer surgery primarily impacts symptoms related to eating, this can affect multiple QOL domains. Many normal social interactions center around meals, and not being able to participate fully may have a detrimental impact on QOL. Patients who experience a high nutritional symptom burden and more eating difficulties may experience poor social well-being and challenges with roles and relationships. Further research is needed to understand patients' postoperative social and role functioning needs.

We observed variations in time to comfort with eating after surgery, which happened for most patients around 1–12 months. Importantly, some patients never felt comfortable with eating. In addition, it appears that multiple behavioral and lifestyle self-management strategies were undertaken, but the type of strategy varied tremendously. This may be due to several potential factors, including use of trial-and-error approaches for choice of strategies, a lack of structured guidance and coaching, and inconsistent efficacy that results in variations in choice of strategies. Factors such as age, gender, level of education, treatments before and after surgery, and time since surgery could also potentially explain the variations observed. Currently, many gastroesophageal cancer patients are given post-operative instructions on nutrition. However, not all patients have access to nutritional counseling services. While registered dietitian nutritionists (RDNs) provide the expertise to meet this challenge, evidence shows that even in comprehensive cancer centers RDN services are not readily available. Current patient-to-RDN ratios exceed 1000:1.<sup>9</sup> Alternative approaches are essential to meet patients' nutritional needs after gastroesophageal cancer surgery.

We had previously postulated that personalized, self-management interventions in the perioperative setting for gastroesophageal cancer should account for patient preferences,

cultural context, and tolerance in dietary patterns.<sup>10</sup> A personalized approach, using classic diet behavior change theories (goal setting, problem-solving, motivational interviewing) may be necessary to help patients adjust successfully to their new diet patterns after surgery. Nutritional symptom characteristics and eating problems are dynamic in frequency and severity, suggesting that effective interventions will need to be flexible in meeting individual needs.

Several limitations of the study warrant further discussion. First, the overall small sample size and single institution design limits the ability to draw conclusions from the findings, and precludes the ability to perform additional meaningful statistical analyses. Second, the cross-sectional design with a single point-in-time assessment may result in recall bias. Third, our findings may be confounded by other variables, such as time since surgery, receipt of adjuvant treatment during survey completion, number of comorbid conditions, and other characteristics. Additional limitations include lack of baseline data (before surgery), lack of comparator, and wide timeframe of assessment (6–12 months post-op). Future studies with a larger sample size using a prospective, longitudinal approach may provide more clinically-relevant information on symptom trajectory and changes in self-management strategies.

In conclusion, patients who have undergone gastroesophageal cancer surgery may experience long-term challenges that can adversely impact their QOL. Many patients adopt their own behavior and lifestyle modifications to manage symptoms. Interventions are needed to support postoperative recovery, adoption of new diet patterns, and symptom management.

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**Table 1.**

## Quality of Life and Symptom Scores

<b>Quality of Life - mean±SD (range), median (IQR) - EORTC-QLQ30; 0-100; higher = better</b>		
<b>Items</b>	<b>Esophageal (N=11)</b>	<b>Gastric (N=20)</b>
Global Health Status	62.9±12.0 (41.7-83.3) 66.7 (50.0-66.7)	64.6±23.9 (16.7-100.0) 66.7 (50.0-83.3)
Physical Functioning	73.3±18.9 (46.7-93.3) 80.0 (53.3-93.3)	78.3±22.6 (13.3-100.0) 86.7 (70.0-93.3)
Role Functioning	63.6±33.2 (0.0-100.0) 66.7 (33.3-100.0)	73.3±32.2 (0.0-100.0) 83.3 (58.3-100.0)
Emotional Functioning	75.0±10.5 (66.7-100.0) 75.0 (66.7-83.3)	79.2±21.0 (41.7-100.0) 83.3 (62.5-100.0)
Cognitive Functioning	77.3±20.1 (33.3-100.0) 83.3 (66.7-100.0)	78.3±21.7 (33.3-100.0) 83.3 (66.7-100.0)
Social Functioning	62.1±29.9 (16.7-100.0) 66.7 (33.3-83.3)	75.0±31.8 (0.0-100.0) 83.3 (66.7-100.0)
Fatigue	45.5±23.5 (11.1-88.9) 33.3 (33.3-66.7)	30.6±27.2 (0.0-100.0) 27.8 (11.1-55.6)
Nausea and vomiting	22.7±25.0 (0.0-66.7) 16.7 (0.0-50.0)	12.5±13.1 (0.0-33.3) 16.7 (0.0-16.7)
Dyspnea	27.3±29.1 (0.0-66.7) 33.3 (0.0-66.7)	15.0±22.9 (0.0-66.7) 0.0 (0.0-33.3)
Insomnia	30.3±27.7 (0.0-66.7) 33.3 (0.0-66.7)	18.3±22.9 (0.0-66.7) 0.0 (0.0-33.3)
Appetite loss	33.3±33.3 (0.0-100.0) 33.3 (0.0-66.7)	26.7±36.8 (0.0-100.0) 0.0 (0.0-66.7)
Constipation	21.2±22.5 (0.0-66.7) 33.3 (0.0-33.3)	15.0±25.3 (0.0-100.0) 0.0 (0.0-33.3)
Diarrhea	24.2±15.6 (0.0-33.3) 33.3 (0.0-33.3)	15.0±25.3 (0.0-66.7) 0.0 (0.0-33.3)
Financial Difficulties	27.3±32.7 (0.0-100.0) 33.3 (0.0-33.3)	40.0±44.1 (0.0-100.0) 33.3 (0.0-100.0)
<b>Disease-Specific Symptoms - mean±SD (range), median (IQR) - 0-100; higher = worse</b>		
<b>Items</b>	<b>Esophageal (N=11) EORTC-QLQ-OES18</b>	<b>Gastric (N=20) EORTC-QLQ-STO22</b>
Eating Restrictions	48.5±23.5 (8.3-91.7) 50.0 (25.0-66.7)	26.7±21.4 (0.0-75.0) 16.7 (8.3-37.5)
Reflux symptoms	28.8±32.6 (0-100) 16.7 (0.0-50.0)	17.2±17.8 (0.0-55.6) 11.1 (0.0-27.8)
Pain	20.2±13.9 (0.0-33.3) 22.2 (11.1-33.3)	23.8±23.3 (0.0-75.0) 25.0 (0.0-33.3)
Trouble swallowing saliva	27.3±32.7 (0.0-100.0) 33.3 (0.0-33.3)	NA
Choked when swallowing	27.3±32.7 (0.0-100.0) 33.3 (0.0-33.3)	NA
Dry mouth	21.2±27.0 (0.0-66.7) 0.0 (0.0-33.3)	25.0±32.2 (0.0-100.0) 16.7 (0.0-33.3)
Trouble with taste	39.4±38.9 (0.0-100.0) 33.3 (0.0-66.7)	20.0±33.2 (0.0-100.0) 0.0 (0.0-33.3)

<b>Quality of Life - mean±SD (range), median (IQR) - EORTC-QLQ30; 0–100; higher = better</b>		
<b>Items</b>	<b>Esophageal (N=11)</b>	<b>Gastric (N=20)</b>
Trouble with coughing	39.4±38.9 (0.0–100.0) 33.3 (0.0–66.7)	NA
Trouble with talking	21.2±16.8 (0.0–33.3) 33.3 (0.0–33.3)	NA
Dysphagia	21.2±20.2 (0.0–55.6) 11.1 (0.0–44.4)	10.6±13.2 (0.0–44.4) 11.1 (0.0–11.1)
Body Image	NA	26.7±25.6 (33.3–100.0) 33.3 (0.0–33.3)

NA=question not included in survey

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