



Dietary alterations and restrictions following surgery for upper gastrointestinal cancers: Key components of a health-related quality of life intervention

Virginia Sun ^{a,*}, Joseph Kim ^b, Jae Y. Kim ^c, Dan J. Raz ^c, Shaila Merchant ^b, Joseph Chao ^d, Vincent Chung ^d, Tracy Jimenez ^e, Elaine Wittenberg ^a, Marcia Grant ^a, Betty Ferrell ^a

^a Division of Nursing Research and Education, Department of Population Sciences, City of Hope, 1500 East Duarte Road, Duarte, CA, 91010, USA

^b Division of Surgical Oncology, Department of Surgery, City of Hope, 1500 East Duarte Road, Duarte, CA, 91010, USA

^c Division of Thoracic Surgery, Department of Surgery, City of Hope, 1500 East Duarte Road, Duarte, CA, 91010, USA

^d Department of Medical Oncology and Therapeutics Research, City of Hope, 1500 East Duarte Road, Duarte, CA, 91010, USA

^e Department of Clinical Nutrition, City of Hope, 1500 East Duarte Road, Duarte, CA, 91010, USA



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Purpose: The surgical treatment of upper gastrointestinal (GI) cancers, specifically esophageal and gastric cancers, often result in extensive health-related quality of life (HRQOL) concerns, particularly those associated with dietary adjustments. This paper provides a review of HRQOL changes following esophagectomy and gastrectomy, and describes key components of an intervention to improve dietary adjustments following surgery.

Methods: Intervention development was informed by 1) current published evidence on HRQOL changes for patients following upper GI surgery, 2) examination of usual post-operative care related to dietary restrictions to identify areas for continued education and support and 3) the inclusion of a conceptual framework (the Chronic Care Model) to guide intervention design and inform the selection of appropriate outcome measures.

Results: Three key components of an HRQOL intervention are identified, and should focus on HRQOL concerns associated with dietary alterations and restrictions following treatment, involve family caregivers, and be tailored and flexible to patient and family caregiver's needs and preferences.

Conclusions: Evidence-based interventions to support long-term dietary alterations and restrictions following upper GI surgery are lacking, despite evidence confirming its impact on morbidity and mortality. Interventions are needed to support dietary adjustments, prevent malnutrition and excessive weight loss, and enhance HRQOL following surgery for upper GI cancers.

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Introduction

Surgery with or without neoadjuvant chemoradiation or chemotherapy is the most established curative intent treatment for upper GI malignancies, including esophageal and gastric

cancers. Esophagectomy and gastrectomy are extraordinarily complex and extensive procedures, and can negatively impact post-operative health-related quality of life (HRQOL). Esophagectomy and gastrectomy procedures share some key features that impact HRQOL in overlapping ways. Although the terms are often used interchangeably, "esophagectomy" is most often performed as an "esophagogastrectomy" with resection of the proximal 1/3 to 1/2 of the stomach along with 2/3 up to the entire the esophagus. Thus the normal capacity for receptive relaxation of the stomach is lost in both esophagectomy and gastrectomy. This is the key physiologic feature that allows normal individuals to consume just three meals a day. Foregut resections also usually

* Corresponding author. Tel.: +1 626 256 4673x63122; fax: +1 626 301 8941.

E-mail addresses: vsun@coh.org (V. Sun), jokim@coh.org (J. Kim), jaekim@coh.org (J.Y. Kim), dratz@coh.org (D.J. Raz), smerchant@coh.org (S. Merchant), jchao@coh.org (J. Chao), vchung@coh.org (V. Chung), tjimenez@coh.org (T. Jimenez), ewittenberg@coh.org (E. Wittenberg), mgrant@coh.org (M. Grant), bferrell@coh.org (B. Ferrell).

involve resection of the vagus nerves which mediate many somatic sensory and digestive processes. Long-term effects of surgical treatment, particularly those associated with dietary alterations and restrictions, can result in significant weight loss, malnutrition, and increased morbidity and mortality. The changes in dietary patterns significantly alter patients' daily routines and can require physical, psychological, social, and spiritual adjustments. The purpose of this paper is to provide a brief review of HRQOL following upper GI surgery and identify key components of a psycho-educational intervention to support upper GI cancer patients and their family caregivers following surgery.

HRQOL changes and symptoms following esophagectomy

There is a robust body of literature that describes HRQOL following esophagectomy, with the majority of evidence originating in Europe and Australia. In multiple population-based studies, HRQOL scores were at its lowest around six weeks following surgery (Avery et al., 2007; Blazeby et al., 2005; Lagergren et al., 2007). Recovery period for HRQOL outcomes ranges between 6 and 12 months (Blazeby et al., 2000; Blazeby, et al., 2005; Brooks et al., 2002; Djärv and Lagergren, 2011a; Lagergren et al., 2007). In multiple population-based studies, patients with poor HRQOL scores at six months following surgery have an increased risk of mortality (Djärv and Lagergren, 2011b; Djärv et al., 2010). After 2–5 years, HRQOL may return to baseline levels, but symptoms persist (Djärv et al., 2008; Donohoe et al., 2011; Gockel et al., 2010).

Delayed recovery is expected in some cases, and while surgeon and hospital size do not influence HRQOL negatively, surgical approach (open versus minimally invasive) may influence recovery time, although findings are not consistent across studies (Djärv and Lagergren, 2011a; van der Schaaf et al., 2013). Predictors of poor postoperative HRQOL include comorbidity, advanced stage of disease, and tumor location (Djärv et al., 2014; Djärv et al., 2009; Koppert et al., 2012). Major postoperative complications, such as anastomotic leak, respiratory failure, pneumonia, and sepsis have long-lasting negative effects on HRQOL in five year survivors (Derogar et al., 2012).

Pre-operative symptoms include fatigue, difficulty sleeping, pain, and cough. Immediately after surgery, the most frequently reported symptoms include fatigue, pain, early satiety, weight loss, and difficulty sleeping. The most common general symptoms at six months following esophagectomy include fatigue, loss of appetite, diarrhea, and dyspnea, with 26%–47% of patients reporting these symptoms (Viklund et al., 2006). Fatigue appears to be worse in patients who received neoadjuvant treatments (Stauder et al., 2013). Esophageal-specific symptoms identified at six months include dysphagia, cough, reflux, dry mouth and esophageal pain, with 22%–27% of patients reporting these problems (Djärv et al., 2008, 2009). At six months after surgery, 59% of patients reported having difficulties with eating (Djärv et al., 2009). Persistent post-operative symptoms at one year include nausea, diarrhea, early satiety, and reflux (Ginex et al., 2013). In a large population-based study, eating problems was the worst symptom (mean score of 35; range of 0–100; higher score = more severe) at six months (Viklund et al., 2006). Other symptoms, such as cough, reflux, pain, dry mouth, dysphagia, and taste, were moderately severe (range of 24–28) (Viklund et al., 2006).

In a large population-based study (N = 402), Wikman and colleagues found that 30% of patients reported the fatigue/pain symptom cluster (pain, fatigue, insomnia, dyspnea) at six months following surgery (Wikman et al., 2014). The reflux/cough cluster, experienced by 27% of patients, included dry mouth, problems with taste, cough, and reflux. The eating difficulties cluster was

characterized by dysphagia, appetite loss, and nausea/vomiting and was experienced by 28% of patients. Patients who experienced the reflux/cough and eating difficulties clusters had a statistically significant risk for mortality (Wikman et al., 2014).

HRQOL changes and symptoms following gastrectomy

Compared to esophagectomy, there is a dearth in large scale, longitudinal studies that describe HRQOL following gastrectomy and adjuvant treatments, with the majority of current evidence originating in Asia and Europe. Similar to esophagectomy, the lowest levels of HRQOL occur in the immediate postoperative period (up to 6 weeks), with partial improvements observed between 6 and 12 months (Bae et al., 2006; Karanicolas et al., 2013; Munene et al., 2012). In a longitudinal study (N = 134), 20%–35% of patients continued to report impaired HRQOL at six months (Karanicolas et al., 2013). In most studies, HRQOL did not recover fully by 12 months post-op (Kaptein et al., 2005; Kong et al., 2012). Patients who underwent proximal resections reported more impaired HRQOL than patients who underwent distal or total resections, and these differences persisted at 18 months after surgery (Karanicolas et al., 2013).

Persistent symptoms are common following resection, and may include fatigue, diarrhea, dysphagia, eating restrictions, and body image disturbances (Kim et al., 2012; Maeda and Munakata, 2008; Maeda et al., 2006). For long-term survivors (2–5 years), HRQOL generally recovered by 6 months after surgery, but at 2 years symptoms such as nausea/vomiting, diarrhea, pain, early satiety, reflux, and sleep difficulties persist (K. Avery et al., 2010; Hwang et al., 2014). In a longitudinal study (N = 195), patients who underwent subtotal resections reported lower weight loss, a smaller number of daily meals, and lower frequency of daily bowel movements compared to patients after total resections, although the differences weren't deemed clinically significant (Jentschura et al., 1997).

Functional disorders following upper GI cancer surgery

Functional disorders that impact physical well-being following surgery include delayed gastric emptying, dumping syndrome, and reflux (Poghosyan et al., 2011). Dysphagia is reported in 21%–56% of patients following esophagectomy, and can be related to benign anastomotic stricture or tumor recurrence (van Heijl et al., 2010). The development of functional disorders is directly linked to anatomic changes and reconfiguration of the upper GI tract after surgery. Symptoms of delayed gastric emptying are reported in 10%–50% of patients after esophagectomy, and include rapid satiety, postprandial discomfort, dysphagia or regurgitation, and risk of aspiration pneumonia (Poghosyan et al., 2011). Delayed gastric emptying symptoms may improve in most patients 3–6 months after surgery, but wide individual variability exists (Poghosyan et al., 2011).

Post-esophagectomy and post-gastrectomy dumping syndrome affects approximately 20–50% of patients (Ginex et al., 2013; Mine et al., 2010; Poghosyan et al., 2011). It is characterized by a broad range of symptoms that occur during the postprandial period and develops progressively based on the quantity and types of food ingested. Most esophagectomy patients experience early dumping syndrome, which occurs rapidly within 20–30 min of meals. Symptoms include palpitations, sweating, flushing, nausea, abdominal cramps, diarrhea, vertigo, and hypotension, which can lead to syncope (Poghosyan et al., 2011). Late dumping syndrome occurs in approximately 25% of patients, and develops 1–3 h after meals. Symptoms are associated with hypoglycemia, and include somnolence, hunger, and trembling (Poghosyan et al., 2011). Up to

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