

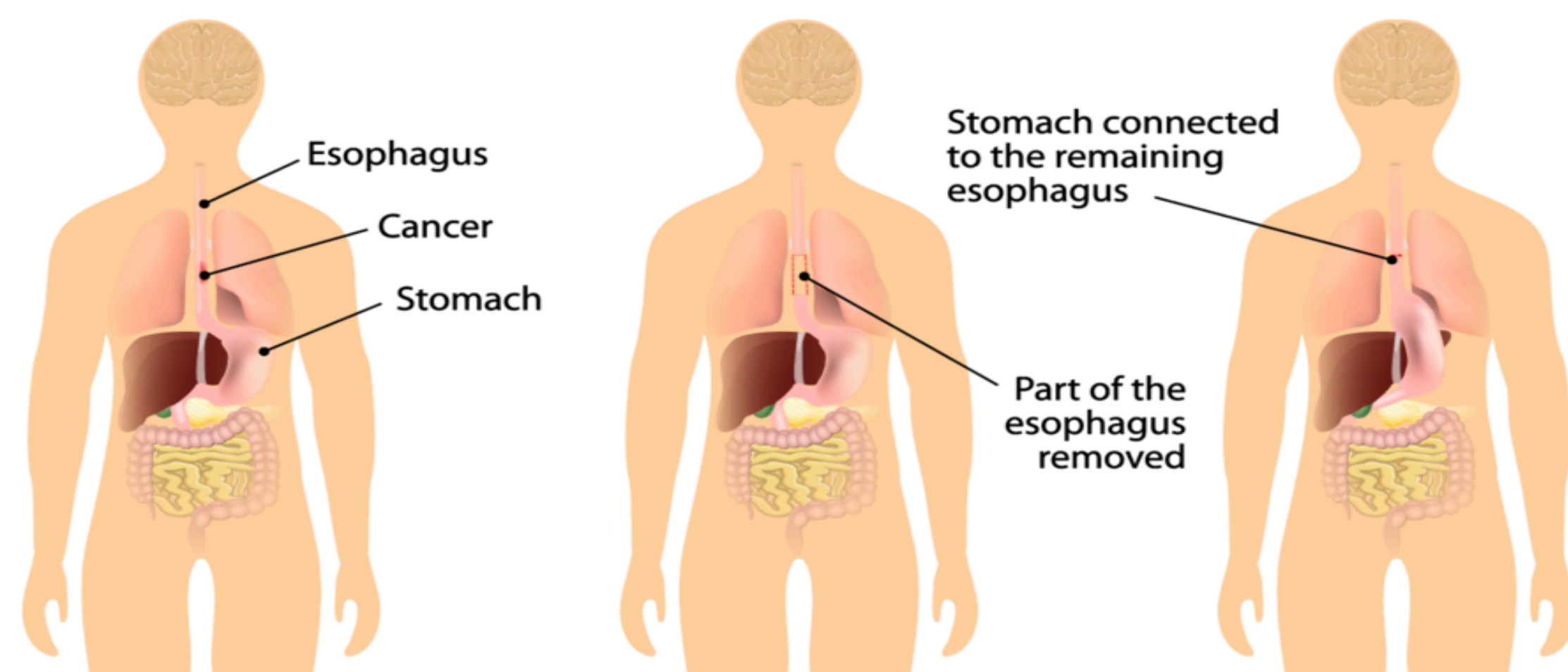
Identifying Unmet Perioperative Support Needs of Patients with Esophageal Cancer: An Exploratory Study

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Background

- Esophageal cancer is a leading cause of cancer-related death worldwide
- Incidence in the US is rising (~17,000 new cases, ~15,000 deaths in 2017)
- Men affected > Women (4:1), diagnosis usually age >60 years

ESOPHAGEAL CANCER



Significance

- Esophageal cancer and treatment affects patients' support needs
- Chemo, radiation, and surgery causes significant morbidity:
 - Physical symptoms: pain, fatigue, dyspnea, poor appetite, diarrhea, dysphagia, cough, etc.
 - Emotional distress: Increased risk of depression and anxiety and high suicide rates
 - Quality of Life (QoL): Intensity of symptoms inverse to health-related QoL
- Patient-Centered Care is one of the National Academy of Medicine's six objectives to improve health care.
- Empathetic patient-centered approach showed a reduction in anxiety levels and better post-surgical recovery
- Patient-centered nursing interventions were more likely to produce optimism and a sense of well-being; Individualizing and coordinating care allowed patients to be more authentic and honest, sharing truthful information that supported effective clinical-decision making, patient-centered practice was associated with improved health outcomes including less discomfort, less concern, and better mental health as well as an efficiency of care with fewer diagnostic tests and referrals ordered by providers
- The patient perspective including recurrent existential concerns such as raising questions about life and death and feeling guilty and responsible for causing the cancer and questions arose about how their cancer could have been diagnosed earlier

Review of the Literature

- Much attention has been devoted to the patterns of symptoms (physical and emotional) following treatment and later to health-related QoL)
- Few studies focused on esophageal cancer patient information needs and satisfaction
- Focus groups have been conducted with esophageal and gastric cancer patients and reported concerns about insufficient information given at discharge concerning what to expect during recovery, continuity of care, which provider to contact for a particular issue, and recognizing the need to contact a health service
- Having a clinical nurse specialist was considered important throughout treatment and follow up when evaluating patient satisfaction; contact during follow up with questions regarding planning and referrals, treatment, and psychosocial concerns including worry, depression and anxiety, and disappointment
- Support Groups provided an opportunity to witness hope and normalization of their experience, yet demonstrated mixed responses
- Nurse-led supportive care interventions decreased hospital length of stay and increased patient satisfaction while maintaining cost effectiveness

Problem

- Supportive care expectations are largely unknown
- Currently there is no standard of care
- Studies largely conducted abroad
- Delayed experiences of longer term survivors is needed
- No studies have been conducted in the United States with the express purpose of eliciting potential unmet patient needs

Purpose & Objectives

To identify the support needs of patients with esophageal cancer in the perioperative setting

1. The primary study objective was to allow patients to identify needs which they perceived were most important
2. A secondary objective was to elicit patient needs not previously acknowledged which require additional resources in order to manage

Participants & Methods

- Qualitative, exploratory
- Convenience sampling at TJUH
- IRB exempt; Verbal consent
- Semi-structured interviews
 - De-identified
 - Recorded
 - Transcribed
 - Analyzed
- Participants (N= 12)

Demographic and Clinical Characteristics	
Characteristics	n
Gender	
Female	4
Male	8
Age (in years) at Diagnosis	
35-45	2
46-55	1
56-65	4
66-75	5
Time From Diagnosis to Study Participation	
0-6 months	4
7-12 months	3
13-18 months	3
19-24 months	0
25-30 months	2
Neoadjuvant Chemoradiation	
Yes	8
No	4
Preoperative	
Yes	2
No	10

Results

Patient Support Needs

“When I want information, I want it when I want it. Which generally is, if you’re suffering, you want it now.”

“You know, you have someone when you say cancer, it’s a physical problem and an emotional problem... [...] both sides of the, you know, you know taking care of physically and also providing an opportunity for the emotional support that I was to need.”

“To get [the caregiver] up to speed on some of the things I needed, it was a little bit of time before she mastered the issues that I faced. Whereas all this downtime in the hospital, she could have been learning in the hospital.”

- I. Information
 - Communication
 - Timing
 - Understanding
 - Confidence
- II. Individualization
- III. Holism
 - Physical
 - Emotional
 - Spiritual
- IV. Anticipation
- V. Goals
- VI. Navigation
- VII. Resources
 - Nursing Care
 - Supports
 - Groups/Centers
 - Caregiver Support

Clinical Implications

- Elicit individual needs
- Evaluate interventions based on patient's goals
- Universal need is effective information sharing
- Optimize perioperative algorithms to enhance comprehensive patient-centered care, patient satisfaction, cancer care coordination, and potentially to impact patient health outcomes