Purpose: The purpose of this study was to identify the perceived unidentified or unmet support needs of patients with esophageal cancer in the perioperative setting through semi-structured interviews. Just as psychological distress had previously been overlooked by clinicians, patients identified issues that have been historically neglected and should be better or more thoroughly addressed. The primary study objective was to allow patients to identify needs which they perceived were most important to them, but were not addressed in the preoperative period. A secondary objective was to elicit patient needs not previously acknowledged which require additional resources in order to manage.

Methods: Semi-structured interviews with open ended questions allowed the researcher to explore experiences in a patient-centered setting. As little was known about the support wishes of patients with esophageal cancer, interviews provided an efficient means of sensitizing the researcher to relevant issues. These unique viewpoints elicited an understanding of the social, cultural, and interpersonal experiences of their shared discourse during disease diagnosis, treatment, and survivorship. Patients were recruited by convenience sampling from the author's institution where approximately 30 operations are performed per year for esophageal cancers. Providers identified potential subjects from two sources: 1) diagnosed esophageal cancer patients through gastroenterology or oncology referrals for preoperative consultations and 2) from the existing list kept by the Division of Thoracic & Esophageal Surgery. Patients who met the inclusion criteria were notified of the study face-to-face in the office, by telephone, postal and electronic mail and offered the opportunity to participate in the study. Interested patients had the opportunity to discuss the study with the researcher prior to giving verbal informed consent. After obtaining verbal informed consent, interviews were held at the time most convenient for the patient, face-to-face or over the telephone, whichever the patient preferred. The researcher began by reviewing the purpose of the study and emphasizing interest in the patients’ unmet needs during their cancer journeys. A verbal consent statement was read prior to recording to emphasize anonymity, confidentiality, and the option to discontinue recording at any time. During the semi-structured interview, additional prompts were given to clarify or address aspects of their experiences; otherwise the researcher allowed the patients to discuss content at their own pace. At the end of the discussion, the researcher reviewed overall themes of the individual to allow for feedback. The recorded interviews were transcribed, de-identified, and confidentially stored by the author. All interviews were analyzed according to qualitative content analysis to draw valid conclusions from data within the context, which has been found to be a suitable method of analysis in similar studies.

Results: Interviews elicited recurrent themes and brought attention to any clinical deficiencies during the treatment period that are particular to the study institution. Reviewing the transcriptions of the interviews revealed a variety of previously
unidentified and unmet support needs. The way in which information is shared including communicating in a timely manner, the provider’s projection of confidence as well as ensuring patient comprehension was notable. Moreover, patient information also yielded the need for individualization of information and the inclusion of both physical and emotional aspects of the patient, or holism. Patients also recognized the clear need for anticipatory guidance as well as goal setting during the course of treatment and recovery. Aid in navigating the healthcare system, nursing care in the home, caregiver and peer support, and additional resources were also major themes recognized by the interviews.

**Conclusion:** After clarifying the support needs of esophageal cancer patients, clinical practice implications should focus on using these findings to optimize perioperative algorithms to enhance patient-centered care. Although resources are readily available including support groups and cancer care centers, many of these resources are often underutilized. Patients expressed appreciation with holistic and individualized information including anticipatory guidance and goal-setting, concerns which may not be met by groups and care centers. The Supportive Care Model explained that to meet the needs of cancer patients, one must tailor interventions based on the careful assessment of the individual’s needs in each domain and tailor specific approaches as well. As interventions helpful to one patient may not necessarily be helpful to another, the individual’s needs, goals, and ways of coping must be matched. The interventions, and the evaluation of the intervention, must be based not on the provider’s perspective and goals, but on the perspective and goals of the patient. Both are required to work in partnership to identify expectations and goals in the assessment process across all need domains within the perioperative esophageal cancer care setting. Interventions and clinical algorithms necessary throughout the patient’s cancer journey must then be tailored to reduce unnecessary distress and enhance the individual’s capacity to cope effectively. As identified in the interviews, patient expectations in which information is relayed, including timeliness, can potentially affect all aspects of care. Unfortunately health care resources are finite and not every need can be addressed, especially as these will vary from patient to patient. One patient expressed utility in interviewing every patient undergoing treatment for esophageal cancer at various times throughout their therapy. Regrettably, the resources needed to conduct interviews and addressing each need may be impractical. Instead, future studies can focus on the patient’s preferences regarding various approaches to information delivery and communication as well evaluation of patient comprehension of this information. Analyzing and extracting the themes from interviews provided a comprehensive picture of the needs perceived by the patients themselves, rather than those projected by clinicians. Recognizing and responding to these expressed needs potentially impacts patient morbidity, satisfaction, and quality of life benefiting the patients themselves, caretakers, clinicians, and the organization as a whole. Truly understanding the support needs of esophageal cancer patients allows clinicians to address their concerns, improve care pathways, and provides a foundation for future study and interventions. Addressing unmet support needs creates opportunities to optimize the perioperative algorithm and to enhance comprehensive patient-centered care, patient satisfaction, cancer care coordination, and potentially to impact patient health outcomes.
Title:
Identifying Unmet Perioperative Support Needs of Patients With Esophageal Cancer:
An Exploratory Study

Keywords:
esophageal cancer, esophagectomy and patient-centered care

References:


**Abstract Summary:**

Esophageal cancer and treatment affects patient support needs. Patients identify support needs regarding information, individualization, holism, anticipation, goals, navigation and resources. Clinicians are encouraged to use patient-identified support needs to optimize perioperative algorithms to enhance patient-centered care, patient satisfaction, cancer care coordination, and potentially to impact health outcomes.

**Content Outline:**

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

II. Significance
1. Esophageal cancer and treatment affects patients’ support needs
2. Chemo, radiation, and surgery causes significant morbidity:
   1. Physical symptoms: pain, fatigue, dyspnea, poor appetite, diarrhea, dysphagia, cough, etc.
   2. Emotional distress: Increased risk of depression and anxiety and high suicide rates
3. Quality of Life (QoL): Intensity of symptoms inverse to health-related QoL
4. Patient-Centered Care is one of the National Academy of Medicine’s six objectives to improve health care.
5. Empathetic patient-centered approach showed a reduction in anxiety levels and better post-surgical recovery
6. 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
6. 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
III. Literature Review
1. Much attention has been devoted to the patterns of symptoms (physical and emotional) following treatment and later to health-related QoL
2. Few studies focused on esophageal cancer patient information needs and satisfaction
3. 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
4. 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
5. Support Groups provided an opportunity to witness hope and normalization of their experience, yet demonstrated mixed responses
6. Nurse-led supportive care interventions decreased hospital length of stay and increased patient satisfaction while maintaining cost effectiveness
IV. Problem
1. Supportive care expectations are largely unknown
2. Currently there is no standard of care
3. Studies largely conducted abroad
4. Delayed experiences of longer term survivors is needed
5. No studies have been conducted in the United States with the express purpose of eliciting potential unmet patient needs
V. Purpose
1. To identify the support needs of patients with esophageal cancer in the perioperative setting
2. The primary study objective was to allow patients to identify needs which they perceived were most important
3. A secondary objective was to elicit patient needs not previously acknowledged which require additional resources in order to manage
VI. Design
1. Qualitative, exploratory
2. Convenience sampling at TJUH
3. IRB exempt; Verbal consent
4. Semi-structured interviews
1. De-identified
2. Recorded
3. Transcribed
4. Analyzed
VII. Results
1. Information
1. Communication
2. Timing
3. Understanding
4. Confidence

2. Individualization
3. Holism
1. Physical
2. Emotional
3. Spiritual
4. Anticipation
5. Goals
6. Navigation
7. Resources
1. Nursing Care
2. Supports Groups/Centers
3. Caregiver Support

VIII. Implications
1. Elicit individual needs
2. Evaluate interventions based on patient’s goals
3. Universal need is effective information sharing
4. Optimize perioperative algorithms to enhance comprehensive patient-centered care, patient satisfaction, cancer care coordination, and potentially to impact patient health outcomes

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