

Supportive Care Needs and Health-Related Quality of Life of Esophageal Cancer Survivors

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ABSTRACT

Objective: The aim of this study is (1) to describe the prevalence and correlates of unmet needs among esophageal cancer survivors (ECS) in Korea and (2) to identify the association between unmet needs and health-related quality of life (HRQOL). **Methods:** We used a cross-sectional descriptive study design. Participants were 118 ECS from a hospital in Korea who received surgery at least 12 months before participating. We collected data including the Supportive Care Needs Survey-short form 34 and to measure HRQOL, the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Core 30 with a self-report questionnaire. **Results:** Participants' mean age was 65.2 years, and 92.4% were male. Among five domains of supportive care needs, unmet need prevalence ranged from 0.8% to

50%. The most commonly reported domains of unmet needs were Health System and Information and Physical and Daily Living. Participants with unmet needs in Psychological Needs, Physical and Daily Living Needs, and Patient Care and Support Needs demonstrated significantly poorer HRQOL in almost all measured domains. **Conclusions:** Our finding suggests that Korean ECS had substantial unmet needs, especially in the Health System and Information domain. Psychological, Patient Care and Support, and Physical and Daily Living Needs were related to HRQOL. The study can advance understanding of priority issues in ECS.

Key words: Esophageal cancer, quality of life, supportive care needs, survivorship

Introduction

Esophageal cancer is the ninth most prevalent cancer and the sixth most common cause of cancer deaths worldwide.^[1] The esophageal cancer incidence in Korea was 1716 in 2002 and 2499 in 2016, suggesting an increase of 45.6% over 14 years.^[2] Following treatment advances, the survival rate has increased as well, going

from 21.4% in 2001 to 2005, 37.4% in 2016, an increase of 16%.^[2] Despite those advances, however, esophageal cancer patients have a poor prognosis.

The dominant treatment for esophageal cancer is surgical resection.^[3] Esophagectomy provides a cure in about 30% of early-stage disease cases and a 5-year

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overall survival rate of about 20%–40%.^[4] Furthermore, about 40% of patients who undergo esophagectomy have a high likelihood of severe complications after surgery.^[5] Despite the fact that this disabling disease has a great impact on patients, few studies have dealt with their unmet needs. Studies have focused largely on information needs and examined specific types of information, such as diagnostic^[6] and prognostic,^[7–9] or focused on early phases in the cancer treatment trajectory,^[6,7] postoperative phase,^[10] or hospital admission^[11] but not on the follow-up phase.

Unmet needs of people with cancer require additional support. Such needs can be multidimensional and include physical, emotional, psychological, social, spiritual, practical, and informational during the cancer journey through diagnosis, active treatment, and posttreatment.^[12,13] A systematic review of 57 studies reported that the prevalence of unmet needs among people with cancer varied in all domains at different time points.^[13] People with cancer report having unmet needs in physical activities (7%–89%), activities of daily living domain (1%–73%), and in psychological (12%–85%), psychosocial (1%–89%), information (6%–93%), communication (2%–57%), spiritual (14%–51%), and sexual (33%–63%) domains. Unmet needs were most prevalent and varied during treatment, but many cancer patients report unmet needs posttreatment.^[13] Most studies of the prevalence of unmet needs of cancer patients focus on survivors of the most common cancers, including breast,^[14–18] colorectal,^[19] prostate,^[20] and lung,^[12,21] with a scarcity of information on esophageal cancer survivors (ECS). Furthermore, while most studies of unmet needs of cancer survivors have been performed in Western populations,^[12,16,19,20,22,23] only a few studies in Korea have been published.^[18,24] The needs of cancer patients, however, should be understood in social and cultural context.^[16]

Optimal cancer care includes not only cutting-edge medical treatment and technology but also supportive care. In a study of people with lung cancer, participants reported a lower level of health-care satisfaction when they had a higher level of unmet supportive care needs.^[12] Furthermore, people with cancer having greater unmet needs tend to have a poorer health-related quality of life (HRQOL),^[14,15,18] thereby adding the burden on existing health-care services and increasing health-care utilization.^[25,26] Thus, understanding the supportive care needs among people with cancer is important to improving their HRQOL. Although much research focuses on the active treatment phase for unmet needs in cancer patients, many participants report unmet needs during the posttreatment phase,^[13] and there is a lack of unmet need information among cancer survivors who had esophagectomy.

In this study, we aim to (1) describe the prevalence and correlates of unmet needs among ECS in Korea and (2) identify the association between unmet needs and HRQOL.

Methods

Study design and setting

A cross-sectional descriptive study design was used. From August to October 2015, we recruited participants through the thoracic surgery outpatient department at a hospital in South Korea. The study proposal and consent form were reviewed and approved by the medical center's Institutional Review Board (IRB Approval #2015-07-124-001).

Participants and procedures

Eligible participants were older than 18 years who had completed esophageal cancer surgery more than 12 months before study participation. If treated by adjuvant therapy, patients had to have completed that therapy at least 3 months before participation. If patients had other previous cancers, those associated treatments had to have been completed at least 5 years before study participation. Patients who were not capable of communication via paper or who developed a new primary cancer after esophageal surgery were excluded.

A nurse screened potential participants via electronic medical records, met with them in a private room at the hospital's thoracic surgery outpatient department, and gave them information about the research. An informed consent form was given to each participant, and questionnaires for the study were distributed after the form was signed. Of the 214 ECS screened, 68 were excluded (17 had developed other cancers, and 51 had their esophageal surgery <12 months before screening). Of the remaining 146 patients, 28 refused to participate in the study due to scheduling issues ($n = 7$), disinterest ($n = 13$), or illness ($n = 8$), leaving 118 for the final sample.

Measures

Sociodemographic and clinical factors

We collected information on sociodemographic factors (gender, age, education, employment status, marital status, and income) with a self-report questionnaire. Clinical factors (the type and stage of esophageal cancer, treatment history, time since diagnosis, current treatment status, and comorbidities [type and number]) were extracted from electronic medical records.

Supportive care needs

We assessed supportive care needs using the 34-item Supportive Care Needs Survey-short form (SCNS-SF34),^[27,28] which measures needs in 5 areas: Physical and Daily

Living (5 items), Psychological (10 items), Patient Care and Support (5 items), Informational (11 items), and Sexuality (3 items). Participants indicated how much assistance they needed with each question over the past month with responses on a five-point Likert scale (1 = no need, not applicable; 2 = need satisfied; 3 = low need; 4 = moderate need; 5 = high need). We calculated the domain score by summing the responses to each of the items within the domain and dividing the sum by the number of items in the domain. A higher score represents a greater perceived need. The Cronbach's alpha coefficients ranged from 0.72 to 0.94.

Health-related quality of life

We assessed HRQOL using the Korean version of the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Core 30 (EORTC QLQ-C30), a 30-item cancer patient questionnaire that measures (a) physical, emotional, role, social, and cognitive functional status, (b) global health, (c) overall QOL, (d) symptoms that cancer patients commonly express, and (e) the financial burdens of cancer and its treatment.^[29,30] The instrument consists of five functioning scales (physical, emotional, role, social, and cognitive), three symptom scales (fatigue, nausea and vomiting, and pain), five single items (dyspnea, appetite loss, sleep disturbance, diarrhea, and constipation), one scale evaluating overall quality of life (QOL), and one separate item evaluating financial impact, total 30 items. Responses are on a four-point Likert scale, except for the items evaluating overall QOL (items 29 and 30), which are on a seven-point Likert scale.

In this study, we used only the five functional status scales and overall QOL scale. We scored the items based on the scoring guide and transformed the raw scores to produce scores from 0 to 100. A higher score indicates a better functioning and HRQOL. The incomplete questionnaires were treated according to the developers' recommendations.^[30] In this study, the Cronbach's alpha coefficients of the six scales ranged from 0.73 to 0.93, and we defined a score difference of 10 or more as a clinically meaningful difference.^[31-33] We derived this figure from studies indicating that the mean difference score is about 10–20 in the QLQ-C30 mean scores for those that reported moderate clinical significance and more than 20 for those that reported high clinical significance.^[31-33]

Data analysis

We used descriptive analyses to present sociodemographic and clinical factors and the prevalence of unmet needs. We analyzed the prevalence of unmet needs by both individual items and domain and defined a need as unmet when the SCNS-SF34 individual item score was moderate to high and a domain need as unmet when its mean score was 4

or higher. For example, if a participant's mean Physical and Daily Living domain score was 4.4, we considered that domain need as unmet because the score indicates moderate to high need (score range: 4–5), whereas if the mean Psychological domain score was 2.9, we rated that need as met because the score indicates no or low need (score range: 1–3). We dichotomized individual items into no or low need (score range: 1–3) and moderate-to-high need (score range: 4–5) and considered the moderate-to-high need as unmet.^[14] We used Chi-square tests to determine an association between sociodemographic and clinical factors with unmet needs and conducted analyses of covariance to examine differences in HRQOL by unmet needs.

Results

Characteristics of study participants

Participants' sociodemographic and clinical characteristics are displayed in Table 1. The mean age of the participants was 65.2 years (standard deviation [SD], 7.9; range, 37–79), 92.4% were men, 95.7% had squamous cell carcinoma, and the mean time since surgery was 35.9 months (SD, 21.0; range, 12–120). Most participants did not receive neoadjuvant treatment (83.1%) nor adjuvant treatment (71.2%), and 51.7% had one or more comorbid conditions.

Supportive care needs and health-related quality of life

The SCNS and EORTC QLQ-C30 findings are displayed in Table 2. Regarding the 5 domains of supportive care needs, the Health System and Information domain was the highest ranked need, whereas sexuality was ranked the lowest by the participants. The mean global QOL score was 62, with 100 being the highest possible score. Among five functional QOL scales, physical function was ranked the highest, followed by emotional function, cognitive function, role function, and social function as the lowest.

Prevalence of unmet needs

Table 3 rank-orders the top 10 reported unmet supportive care needs by individual SCNS item. Of note, 7 of the top-ranked needs were in the Health System and Information domain, followed by the Physical and Daily Living domain and the Psychological domain. The top unmet need, "to be informed about things you can do to help yourself get well," was reported by 59 (50%) of the study participants.

Association between unmet needs and health-related quality of life

Table 4 shows the differences in HRQOL among ECS who reported met and unmet needs, along with

Table 1: Sociodemographic and clinical variables of the study participants (n = 118)

Characteristic	n (%)
Gender	
Men	109 (92.4)
Women	9 (7.6)
Age (years), mean (SD)	65.22 (7.90)
<50	3 (2.5)
50-59	25 (21.2)
60-69	52 (44.1)
70-79	38 (32.2)
Marital status	
With spouse	102 (86.4)
Without spouse	16 (13.6)
Level of education	
Elementary school graduation	31 (26.3)
Middle school graduation	18 (15.3)
High school graduation	36 (30.5)
≥College graduation	33 (28.0)
Employed	
Yes	32 (27.1)
No	86 (72.9)
Monthly income, \$	
<2000	69 (58.5)
≥2000	49 (41.5)
Body mass index (m ² /kg), mean (SD)	21.04 (2.67)
> 18.5	25 (21.2)
18.5-22.9	64 (54.2)
23.0-24.9	20 (16.9)
≥25.0	9 (7.6)
Tumor histology (n=117)	
Squamous cell carcinoma	112 (95.7)
Adenocarcinoma	5 (4.3)
Stage at diagnosis (n=117)	
I	44 (37.6)
II	48 (41.0)
III	25 (21.4)
Esophageal replacement	
Stomach	109 (92.4)
Jejunum	6 (5.1)
Colon	3 (2.5)
Neoadjuvant treatment	
CCRT	20 (16.9)
None	98 (83.1)
Adjuvant treatment	
Chemotherapy	28 (23.9)
Radiation therapy	6 (5.1)
None	84 (71.2)
Time since surgery (months), mean (SD)	35.87 (20.98)
12-23	44 (37.3)
24-35	24 (20.3)
36-47	19 (16.1)
48-60	15 (12.7)
≥60	16 (13.6)
Comorbidity	
Hypertension	37 (31.4)
Diabetes mellitus	20 (16.9)

Contd...

Table 1: Contd...

Characteristic	n (%)
Benign prostate hypertrophy	13 (11.0)
Pulmonary disease	7 (5.9)
Cerebrovascular disease	6 (5.1)
Cardiovascular	5 (4.2)
Musculoskeletal disease	5 (4.2)
Liver disease	4 (3.4)
Digestive system disease	3 (2.5)
None	57 (48.3)

CCRT: Concurrent chemoradiation therapy; SD: Standard deviation

clinically meaningful differences. Participants with unmet Psychological and Physical and Daily Living Needs demonstrated significantly poorer HRQOL in all measured domains. Participants with unmet needs in the Psychological and the Physical and Daily Living domains yielded the worst scores in all functions and in global QOL; participants who had an unmet need in the Patient Care and Support domain reported poorer emotional and social functioning, with some clinically meaningful differences.

Discussion

To the best of our knowledge, this study of 118 Korean ECS is the first to examine the unmet need prevalence, and the association between unmet needs and HRQOL, among ECS in Asia. Since this is the first study using the SCNS to assess ECS' needs, we cannot compare it to other unmet need studies of ECS. Compared with studies of the needs of survivors with other types of cancer in other cultures,^[16,34] however, Korean ECS in this study reported relatively higher levels of unmet needs across all domains. The significant proportion of ECS with unmet needs in Korea shown in our research suggests a need for a supportive care survivorship program.

Participants identified the Health System and Information domain as having the most unmet needs. Similarly, among the 34 individual items on the SCNS, 8 of those top-ranked needs were in the Health System and Information domain. These findings are in agreement with a systematic review that found that colorectal cancer survivors tended to need information about treatment and recovery throughout the posttreatment phase.^[13] Furthermore, the traditional medical follow-up and screening procedures tend to overlook the needs of survivors and often fail to meet their Health System and Information needs.^[17]

Our study findings are more consistent with cancer patients in Korea,^[18,35] China,^[14,36] Hong Kong,^[16] and Singapore^[17] than with those in Western countries, where the most common needs are psychological,^[22,34,37] suggesting that cancer survivors in Western societies have a greater need for psychological support than those in Asian societies. Furthermore, Korean ECS may reflect the

Table 2: Supportive care needs and European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Core 30 of the participants

Variable	Category	Mean (SD)	Minimum	Maximum
SCNS	Psychological	20.87 (24.25)	0	100
	Health system and information	28.29 (17.53)	0	86.64
	Physical and daily living	27.03 (23.25)	0	100
	Patient care and support	18.69 (16.48)	0	90
	Sexuality	12.21 (20.11)	0	100
EORTC QLQ-C30	Global QOL	62.01 (18.83)	0	83.33
	Function scales			
	Physical	80.90 (18.51)	0	100
	Role	77.40 (24.41)	0	100
	Emotional	78.95 (25.78)	0	100
	Cognitive	77.82 (19.13)	16.67	100
	Social	70.76 (26.32)	0	100

Possible range of all values, 0-100. EORTC QLQ-C30: European Organization for Research and Treatment of Cancer QOL Questionnaire-Core 30; QOL: Quality of life; SCNS: Supportive Care Needs Survey; SD: Standard deviation

Table 3: Top 10 unmet supportive care needs ranked as moderate or high (n = 118)

Rank	Domain	Individual items	n (percentage of unmet needs)
1	Health system and information	29. To be informed about things you can do to help yourself get well	59 (50.0)
2		23. To be given written information about important aspects of your care	45 (38.1)
3		24. To be given information (written, diagrams, drawings) about aspects of managing your illness and side effects at home	41 (34.7)
4		34. To have one member of hospital staff with whom you can talk to about all aspects of your condition, treatment, and follow-up	41 (34.7)
5		27. To be informed about your test results as soon as feasible	35 (29.7)
6	Physical and daily living	2. Lack of energy/tiredness	26 (22.0)
7	Health system and information	25. To be given explanations of those tests for which you would like explanations	25 (21.2)
8		26. To be adequately informed about the benefits and side effects of treatments before you choose to have them	23 (19.5)
9	Psychological needs	13. Keeping a positive outlook	20 (16.9)
10	Physical and daily living	3. Feeling unwell	19 (16.1)

cultural tendency to uncritically embrace authority and to be fearful of asking questions or of being considered as problematic if they question health-care providers.^[38] Thus, medical professionals should play an active role in providing information rather than expecting patients to initiate asking questions about their cancer or treatment. Cross-cultural research is needed to examine this phenomenon and to identify other possibilities. Furthermore, our results suggest that the current survivorship program for patients with esophageal cancer in Korea may not meet their supportive care needs. Participants were posttreatment, and most expected to live their lives independently. As such, they indicated a high level of unmet needs in knowledge, in reassurance on the prognosis of their disease, and in detailed self-management strategies. While many hospitals in Korea have centers for cancer education and support and offer comprehensive resources and materials, patients may not accept or even pay attention to them, or they may consider them insufficient or inappropriate. Health-care providers should ask patients whether the information they have is adequate or if they would like more.^[10]

A qualitative study, however, has revealed that too much information can overwhelm or confuse some cancer survivors, reminding them of their cancer experience and provoking fears of a recurrence.^[17] Cancer patients differ in their level of information need, and some may choose to remain uninformed.^[21] Qualitative studies of ECS' informational needs are needed to explore more detailed needs assessments and provide personalized information. According to an Internet-based intervention study, promoting communication between patients and their health-care providers is critical because it can enable cancer survivors to take an active role in decision-making at their desired level and to make informed choices regarding their treatment options and posttreatment care plans.^[39] One study found that a question prompt sheet that helped esophageal cancer patients gain desired information via consultation with their health-care providers was both feasible and effective; patients indicated that they appreciated the tool, which enabled them to interact with their physician more actively without increasing consultation time.^[8] This type of approach could form the basis of future intervention studies

Table 4: Association between met and unmet needs and health-related quality of life among participants

HRQOL	Physical function		Role function		Emotional function		Cognitive function		Social function		Global QOL	
	LS mean (SE)	P	LS mean (SE)	P	LS mean (SE)	P	LS mean (SE)	P	LS mean (SE)	P	LS mean (SE)	P
Supportive care needs												
Psychological												
Met	85.88 (1.65)	<0.001*	85.37 (2.18)	<0.001**	88.66 (1.97)	<0.001**	81.93 (1.94)	<0.001*	76.46 (2.54)	<0.001**	68.47 (1.62)	<0.001**
Unmet	68.07 (2.65)		56.88 (3.52)		53.96 (3.22)		67.26 (3.11)		56.10 (4.13)		44.90 (2.62)	
Health system and information												
Met	86.31 (3.55)	0.090	80.24 (4.83)	0.512	85.85 (4.79)	0.111	80.20 (3.89)	0.496	75.13 (5.08)	0.338	63.90 (3.77)	0.541
Unmet	79.52 (1.74)		76.68 (2.44)		77.20 (2.41)		77.22 (1.96)		69.65 (2.55)		61.32 (1.86)	
Physical and daily living												
Met	87.51 (1.56)	<0.001**	85.94 (2.16)	<0.001**	86.66 (2.25)	<0.001**	83.50 (1.87)	<0.001*	77.37 (2.49)	<0.001**	68.60 (1.66)	<0.001**
Unmet	65.26 (2.43)		57.15 (3.34)		60.69 (3.49)		64.38 (2.91)		55.10 (3.85)		45.95 (2.57)	
Patient care and support												
Met	85.67 (2.26)	0.005	82.46 (3.04)	0.022	86.58 (2.95)	<0.001*	80.20 (2.54)	0.200	77.86 (3.13)	0.002*	65.52 (2.43)	0.042
Unmet	76.29 (2.20)		72.51 (2.99)		71.58 (2.90)		75.53 (2.49)		63.91 (3.08)		58.31 (2.37)	
Sexual												
Met	80.07 (2.05)	0.549	77.06 (2.81)	0.846	81.04 (3.11)	0.354	79.74 (2.25)	0.182	72.47 (3.28)	0.470	63.01 (2.16)	0.392
Unmet	82.03 (2.51)		77.92 (3.45)		75.81 (4.01)		74.93 (2.77)		68.19 (4.22)		60.06 (2.65)	

HRQOL: Health-related quality of life; LS: Least squares; QOL: Quality of life physical function was adjusted for employment; BMI: stage, and comorbidity. Role function was adjusted for marital status, employment, and BMI. *The mean difference score was about 10-20 (i.e., of moderate clinical significance). **That the mean difference score was >20 (i.e., of high clinical significance). SE: Standard error

focused on assessing and meeting patients' informational needs and improving their HRQOL.

Our finding of a strong relationship between unmet needs and HRQOL is in agreement with prior research.^[14-16,40] Among Chinese cancer survivors, for example, those with more unmet Psychological Needs and Physical and Daily Living Needs experienced a poorer overall HRQOL.^[14] Similarly, in all HRQOL domains, our study participants with unmet needs in Psychological and Physical and Daily Living reported significantly lower scores. In all the functioning and global QOL scores, we observed clinically meaningful differences (≥ 10 points) in those survivors with unmet needs in Psychological and Physical and Daily Living, indicating that physical and psychological unmet needs, as well as insufficient and inadequate survivorship care plans, could have substantial effects on HRQOL among ECS. Our finding suggests that HRQOL could be improved through interventions based on the evaluation of specific unmet needs.

This study has several limitations. First, the cross-sectional design prevented us from identifying causal relationships. Second, the convenience sampling did not allow us to generalize our results to other ECS. Third, we cannot rule out the chance of selection bias arising from our inability to collect data for participants who refused to participate in the study and who may have had different levels of HRQOL as well as met and unmet needs.

Despite these limitations, there are notable strengths of the current study. To the best of our knowledge, the current study is the first study to examine the association between unmet needs and HRQOL among ECS in Asia. It shows that Korean ECS reported the great unmet supportive care needs which were associated with lower HRQOL. This study would be useful for health-care providers to detect and prioritize the problems and develop a tailored survivorship care program for ECS based on their specific unmet needs and cultural factors, which may improve their HRQOL.

Conclusions

Our study does identify the unmet needs of posttreatment ECS in Korea, reporting, in particular, that the greatest unmet needs were in Health System and Information, and that Psychological and Physical and Daily Living unmet needs were associated with poorer HRQOL. These findings can improve our understanding of priority issues in this understudied population. In addition, identifying clinically meaningful differences in HQOL between cancer survivors with met and unmet needs can help us formulate studies of interventions designed to target health outcomes. Our findings highlight the importance of integrating supportive care for ECS into routine cancer survivorship care in Korea.

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Conflicts of interest

There are no conflicts of interest.

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