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
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\(^5,9\) 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. The instrument consists of five functioning scales (physical, emotional, role, social, and cognitive), three symptom scales (fatigue, nausea and vomiting, and pain), five single terms (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. 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. We derived this figure from studies indicating that the mean difference score is about 10–20 in the QLQ-L C30 mean scores for those that reported moderate clinical significance and more than 20 for those that reported high clinical significance.

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. 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
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

| Characteristic | n (%) |
|----------------|-------|
| Gender | |
| Men | 109 (92.4) |
| Women | 9 (7.6) |
| Age (years), mean (SD) | |
| <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 (m²/kg), mean (SD) | |
| >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 (82.4) |
| Radiation therapy | 6 (17.6) |
| None | 84 (71.2) |
| Time since surgery (months), mean (SD) | |
| 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) |

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

| 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
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.

| 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     |

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

| 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)                     |

Table 3: Top 10 unmet supportive care needs ranked as moderate or high (n=118)
Table 4: Association between met and unmet needs and health-related quality of life among participants

| HRQOL                                  | Physical function | Social function | Cognitive function | Emotional function | Role function | Global QOL |
|----------------------------------------|-------------------|-----------------|-------------------|--------------------|---------------|------------|
| Met                                    | LS mean (SE)      | LS mean (SE)    | LS mean (SE)      | LS mean (SE)       | LS mean (SE)  | LS mean (SE) |
| Psychological                            |                   |                 |                   |                    |               |            |
| Met                                    | 85.68 (1.65)      | 76.51 (2.28)    | 76.91 (2.17)      | 77.64 (2.24)       | 75.13 (2.68)  | 77.86 (3.13) |
| Unmet                                  | 68.57 (2.65)      | 69.26 (2.43)    | 73.46 (2.06)      | 76.18 (2.31)       | 70.11 (2.82)  | 72.67 (2.49) |
| Physical and daily living               |                   |                 |                   |                    |               |            |
| Met                                    | 86.21 (2.95)      | 77.31 (2.42)    | 76.86 (2.24)      | 77.31 (2.42)       | 75.21 (2.59)  | 72.47 (3.28) |
| Unmet                                  | 67.29 (2.20)      | 67.92 (2.31)    | 71.31 (2.26)      | 70.29 (2.31)       | 69.01 (2.68)  | 70.69 (2.62) |
| Patient care and support                |                   |                 |                   |                    |               |            |
| Met                                    | 85.67 (2.26)      | 77.61 (2.42)    | 76.91 (2.17)      | 77.64 (2.24)       | 75.13 (2.68)  | 77.86 (3.13) |
| Unmet                                  | 68.57 (2.65)      | 69.26 (2.43)    | 73.46 (2.06)      | 76.18 (2.31)       | 70.11 (2.82)  | 72.67 (2.49) |
| Sex                                    |                   |                 |                   |                    |               |            |
| Met                                    | 80.07 (2.65)      | 76.06 (2.81)    | 76.91 (2.17)      | 77.64 (2.24)       | 75.13 (2.68)  | 77.86 (3.13) |
| Unmet                                  | 72.47 (3.28)      | 72.67 (3.27)    | 71.31 (2.26)      | 70.29 (2.31)       | 69.01 (2.68)  | 70.69 (2.62) |

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. Emotional function was adjusted for age, marital status, and substitute of surgery. Cognitive function was adjusted for employment and BMI. Social function was adjusted for age, marital status, and BMI. Global QOL 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). BMI: Body mass index; SE: Standard error.
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Conflicts of interest
There are no conflicts of interest.

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