Needs regarding care and factors associated with unmet needs in disease-free survivors of surgically treated lung cancer

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Background: To evaluate the long-term needs of lung cancer survivors and to explore factors associated with unmet need.

Patients and methods: We recruited lung patients treated with curative surgery from 2001 through 2006 at two centers in Korea. Needs in the domains of information, supportive care, education and counseling, and socioeconomic support were measured. We selected the four most frequently reported items of unmet need among 19 items in four domains.

Results: The most frequently reported unmet needs were Complementary and alternative medicine (CAM) and folk remedies (59.8%) in the Information domain, Counseling and treatment of depression and anxiety (83.5%) in the Supportive care domain, diet, exercise and weight control (55.1%) in the Education and counseling domain and Financial support (59.8%) in the Information domain. Counseling and treatment of depression and anxiety (63.5%) in the Supportive care domain, diet, exercise and weight control (55.1%) in the Education and counseling domain and Financial support (59.8%) in the Information domain were measured. We selected the four most frequently reported items of unmet need among 19 items in four domains.

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(90.4%) in the socioeconomic support domain. Unmet needs for psychological treatment was significantly greater in participants who were employed (adjusted odds ratio [aOR], 2.25; 95% confidential interval [CI], 1.12 to 4.53). Unmet needs for diet, exercise and weight control were significantly greater in participants who had not received chemotherapy (aOR, 1.76; 95% CI, 1.09 to 2.85). Unmet need for financial support was greater in participants who were married (aOR, 4.14, 95%CI, 1.12 to 15.22) and those who had not received chemotherapy (aOR, 5.91, 95%CI, 1.91 to 18.31).

**Conclusion:** There were substantial unmet needs for information regarding psychological support, education for diet and exercise, and financial support among lung cancer survivors.

**Key words:** lung cancer, survivors, unmet need

**introduction**

Although advances in early detection and treatment strategies for lung cancers have increased their numbers, lung cancer survivors face numerous physical and psychosocial difficulties after treatment that influence health-related quality of life (HRQOL) [1–3]. Survivorship care planning (SCP) in the transition from intensive treatment to survivorship can effectively address these physical and psychosocial difficulties. SCP for lung cancer survivors includes periodic visits to update their medical histories, physical examinations and annual surveillance for detecting recurrent lung cancer and secondary primary cancers, and the management of long-term effects, rehabilitation, health promotion and psychosocial support [3–10].

Although survivorship is now recognized as a unique and essential phase in the cancer control continuum [8, 10–12], limited evidence suggests that patients are typically dissatisfied with care during this time [13–17], and that this dissatisfaction may lead to deficits in the quality of care that cancer survivors receive [5, 18, 19]. For example, information may be obtained from specialist breast care services by breast cancer patients at the time of diagnosis. However, two years later, breast cancer patients reported receiving new information primarily from media sources such as women’s magazines, and reported discomfort in requesting information from medical providers [20]. Furthermore, although the number of lung cancer survivors has increased [21–24], most studies focus on breast cancer [4, 7, 19, 25], prostate [17, 26], colorectal [17, 26], and gynecologic cancers [17, 19], or communication and role play among care providers [3, 5, 7, 27]. Few studies focus on comprehensive care for lung cancer survivors after pneumonectomy or on long-term survivorship that promotes healthy lifestyles [5, 17]. Because recent studies show that lung cancer survivors suffer substantial burdens strongly associated with poor clinical outcomes, such as fatigue, dyspnea, intrusive stress symptoms, and lower satisfaction with their health care [28–30], further research is needed to test effective interventions, such as counseling about health behaviors [19, 31].

We conducted self-administered surveys to assess the needs of lung cancer survivors for care and to explore the factors associated with unmet needs.

**methods**

The Korean National Cancer Center initiated the Lung Cancer Survivorship Study, which focuses on HRQOL, health behaviors, screening for secondary cancers and rehabilitation in 2007. To evaluate the unmet needs of lung cancer survivors for long-term care after recovery from cancer and its treatment, we administered the questionnaire 1 year or more after their curative surgery.

**participants**

We identified 2,049 patients who had been treated for lung cancer at two hospitals in South Korea, the National Cancer Center (NCC) and Samsung Medical Center (SMC), from 2001 through 2006. We collected information about primary cancer site, date of diagnosis, stage, type of treatment and other clinical characteristics from hospital cancer registries. Patients were eligible to participate if they 1) had a past diagnosis of lung cancer, 2) were treated with curative surgery and 3) had no other history of cancer. We excluded from this analysis subjects whose cancer had recurred after curative surgery at the time of recruitment, regardless of treatment. We also excluded patients who underwent video-assisted thoracic surgery because it was not carried out often from 2001 to 2006. Therefore, all patients in this study underwent pulmonary resection via open thoracotomy. The Institutional Review Boards of both NCC and SMC reviewed and approved the protocol of our study. All participants provided written informed consent.

**recruitment procedures**

We selected the interview method with the intent of increasing the response rate and minimizing missing data in the questionnaire. Eligible subjects were contacted by telephone, and those who agreed to participate were presented with the questionnaire by a trained interviewer, either at home or in the clinic. Participants completed the questionnaire on their own, however, so as to avoid having the interviewer influence their answers. We collected information about the primary cancer site, date of diagnosis, stage, type of treatment and other clinical characteristics from the hospital cancer registries.

**selection of the items included in the survey**

We based the questionnaire used in the present study on published research [3–9]. It contained 19 items covering 4 domains of need: Information (5 items), Supportive Care (4 items), Education and Counseling (6 items), and Socioeconomic Support (4 items).

**measures**

The survey asked, ‘What was your level of need after treatment of cancer for help with...’ for each of the 19 items. For example, ‘getting information for your treatment plan and prognosis,’ ‘counseling for diet, exercise and weight control’ and ‘counseling for sexual problems.’ The response options were ’1 - not at all’, ’2 - a little’, ’3 - somewhat’ and ’4 - very much’ to determine the level of need associated with each item. In addition, the survey asked whether patients received each health care service, and, if so, where they received the care. We classified the responses into two groups. To identify the most pressing unmet needs among the many needs of the
patient population, we defined an ‘unmet need’ as a service the participant needed ‘very much’ but did not receive. All other responses were classified as ‘need met.’

### statistical analyses

We conducted descriptive statistical analyses to characterize the overall study sample and to examine the levels of overall needs and unmet needs. We then selected the four most frequently reported unmet need items in each domain considering the level of need. We used chi-square tests to assess the relationships of socio-demographic and clinical characteristics and high unmet needs. Each independent factor that was statistically significant at the 0.10 level of probability in univariate analysis was entered into the final multivariate logistic regression model, with $P < 0.05$ taken as statistically significant. We obtained a best-fit in that model using a stepwise elimination procedure. All statistical tests were two-sided. All statistical tests were two-sided and carried out using SAS version 9.2 (SAS Institute, Inc., Cary, NC, USA).

### results

### subjects and recruitment results

Of the 2,049 potentially eligible lung cancer patients identified from the participating registries, 126 (6.1%) had died. We made multiple attempts to contact the others by postcard or telephone but were unable to reach 290 (14.2%) patients; the most frequent reason for contact failure was a change of address or telephone number. Of the 1,633 (79.7%) patients who were contacted, 727 (35.5%) refused to participate. The reasons given most frequently were that the survey was inconvenient, that it took too long to complete or that the patient felt too ill. Ultimately, 906 (44.2%) patients consented to participate in the survey. Of these, we excluded 76 patients who had recurrent cancer at the time of contact failure and high unmet needs. Each independent factor that was statistically significant was entered into the final multivariate logistic regression model, with $P < 0.05$ taken as statistically significant. We obtained a best-fit in that model using a stepwise elimination procedure. All statistical tests were two-sided. All statistical tests were two-sided and carried out using SAS version 9.2 (SAS Institute, Inc., Cary, NC, USA).

### participant characteristics

Table 1 summarizes the sociodemographic and clinical characteristics of the participants. The mean age was 62.9 years (SD = 1.6), and there were more males than females (76.8% versus 23.2%, respectively). The mean time since diagnosis was 4.2 years (SD = 1.6). Detailed information is presented in Table 1.

### overall levels of need

We classified level of need as ‘very much’ or ‘other’. The highest level of need was seen in the Information domain, where the items most frequently cited as being needed ‘very much’ were Treatment plan and prognosis (56.1%), General information on cancer (50.6%), and Cancer screening (43.2%). The Supportive Care domain showed moderate levels of need, including a need for Side effects of cancer therapy (36.2%) and a need for Management of pain, fatigue, and appetite loss (32.6%). The Education and Counseling domain showed high levels of need only for Diet, exercise and weight control (36.3%). Moderate levels of need were seen for Socioeconomic Support, including the need for Financial support (24.8%) and the need for

| Table 1. Sociodemographic and clinical characteristics of lung cancer survivors (n = 830) |
|-----------------------------------------------|-----|-----|
| **Characteristics**                          | **N** | **Percent** |
| Age (years)                                  |     |       |
| <50                                          | 58  | 7.0  |
| 50–64                                        | 379 | 45.6 |
| 65–79                                        | 390 | 47.0 |
| ≥80                                          | 3   | 0.4  |
| Gender                                       |     |       |
| Female                                       | 193 | 23.2 |
| Male                                         | 637 | 76.8 |
| Education (n = 828)                          |     |       |
| <High school graduation                     | 387 | 46.7 |
| ≥High school graduation                     | 441 | 53.3 |
| Marital status                               |     |       |
| Unmarried, divorced or widow                 | 66  | 7.9  |
| Married                                      | 764 | 92.1 |
| Employment (n = 829)                         |     |       |
| Unemployed (never having job, retirement or loss of job under employment) | 507 | 61.2 |
| Employed                                     | 322 | 38.8 |
| Monthly income (n = 829)                     |     |       |
| <US $2,000                                   | 446 | 53.8 |
| ≥US $2,000                                   | 383 | 46.2 |
| Family number                                |     |       |
| Living alone                                 | 1   | 0.1  |
| 2–4 members                                  | 794 | 95.7 |
| ≥5 members                                   | 35  | 4.2  |
| Smoking status                               |     |       |
| Current smokers                              | 60  | 7.2  |
| Former or never smokers                      | 770 | 92.8 |
| Body mass index (n = 816)                    |     |       |
| ≤18.5                                        | 47  | 5.8  |
| >18.5                                        | 769 | 94.2 |
| Stage                                         |     |       |
| 0–I                                          | 526 | 63.4 |
| II–III                                       | 304 | 36.6 |
| Time since diagnosis                         |     |       |
| <12 months                                   | 18  | 2.2  |
| 13–23 months                                 | 202 | 24.4 |
| 24–59 months                                 | 466 | 56.3 |
| <5                                           | 141 | 17.0 |
| ≥60 months                                   | 141 | 17.0 |
| Comorbidity                                  |     |       |
| Cardiovascular disease                       | 17  | 2.1  |
| Heart Disease(angina, cardiac Infarction, chronic heart failure) | 51  | 6.2  |
| Diabetes                                     | 98  | 11.9 |
| Chronic liver disease                        | 13  | 1.6  |
| Chronic lung disease (asthma, chronic obstructive pulmonary disease) | 161 | 19.5 |
| Hypertension                                 | 65  | 7.9  |
| Gastrointestinal disease                     | 89  | 10.7 |
| Musculoskeletal disease (degenerative arthritis, rheumatoid arthritis) | 89  | 10.7 |
| Chronic renal disease                        | 6   | 0.7  |
| Others                                       | 89  | 10.7 |
| Not at all                                    | 376 | 45.5 |

Continued
Community resources (22.3%). The lowest levels of need were seen for sexuality, such as the need for Sexual function (6.8%) and Infertility (5.5%). (Figure 1).

primary items of unmet need
We selected the four most frequently reported items of unmet need in each domain. We selected only those items where the level of ‘very much’ need was higher than 15%. Therefore, the highest items of unmet need were Financial support (90.4%), Counseling and treatment for depression and anxiety (63.5%), CAM and folk remedies (59.8%) and Diet, exercise and weight control (55.1%) (Figure 1).

factors associated with items of high unmet need
We carried out univariate analyses between sociodemographic and clinical characteristics and items of high unmet need (Table 2). In domain of counseling and treatment for depression and anxiety, marital status ($P = 0.088$), employment status ($P = 0.036$), and BMI ($P = 0.072$) were associated with this need. In domain of diet, exercise and weight control, level of education ($P = 0.078$), experience of chemotherapy (0.020) and radiation therapy ($P = 0.038$) were significant factors within $P < 0.10$. As for domain of financial support, 6 factors were related to this need; marital status ($P = 0.010$), education ($P = 0.090$), employment status ($P = 0.048$), monthly income ($P = 0.021$), BMI ($P = 0.004$), and chemotherapy ($P = 0.002$). However, unmet need for CAM and folk remedies, there were no significant variables.

descriptors of items of high unmet need
We examined predictors of items of high unmet need regarding three items because there was no significant variable in need for CAM and folk remedies through univariate analyses. Unmet need for Counseling and treatment for depression and anxiety was predicted by employment status: unmet need was significantly greater in participants who were employed (adjusted odds ratio [aOR], 2.25; 95% confidential interval [CI], 1.12 to 4.53). Unmet need for diet, exercise and weight control was significantly greater in participants who had not received chemotherapy (aOR, 1.76, 95% CI, 1.09 to 2.85). Finally, unmet need for Financial support was greater in survivors who were married (aOR, 4.14, 95% CI, 1.12 to 15.22) and

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>N</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chemotherapy (n = 824)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not received</td>
<td>542</td>
<td>65.8</td>
</tr>
<tr>
<td>Received</td>
<td>282</td>
<td>34.2</td>
</tr>
<tr>
<td>Radiotherapy (n = 824)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not received</td>
<td>716</td>
<td>86.9</td>
</tr>
<tr>
<td>Received</td>
<td>108</td>
<td>13.1</td>
</tr>
</tbody>
</table>

Figure 1. Care needs and unmet needs in lung cancer survivors.
those who had not received chemotherapy (aOR, 5.91, 95% CI, 1.91 to 18.31) (Table 3).

**discussion**

Similar to recommendations from the American Cancer Society, the President's Cancer Panel and the Institute of Medicine [11, 32, 33], the results of this study suggest that survivors should receive appropriate SCP that includes information on health care (general information about cancer, prognosis, screening for a second cancer and comorbidity management), supportive care (care therapeutic side-effects, or management of pain, fatigue and anorexia, management of depression and anxiety, and rehabilitation),...
education (diet and exercise counseling, smoking cessation and genetic counseling) and socioeconomic support (information related to community resources, potential insurance, employment and financial challenges). Our results also showed that although many cancer survivors were satisfied with the cancer-related information they received, such as prognosis and supportive care for complication such as pain and fatigue, there were substantial unmet needs for information about CAM, diet and exercise education, psychological support and financial support. This is consistent with findings from earlier studies showing that most patients have moderate or severe unmet supportive care needs [17, 19, 28–30] that remains important throughout the continuum of care. National health insurance, together with Medicaid for the poor, covers almost in the whole Korean population. Coverage for serious illnesses such as cancer is especially high, and the patient’s out-of-pocket share was 10% in 2005 and decreased to 5% in 2010. Supportive care, however, is not always covered.

These findings may reflect significant discordances in expectations about many aspects of care according to the different assumptions of patients and providers about providers’ roles after cancer treatment. There may be a lack of provider awareness of the potential benefits of a healthy lifestyle and a diffusion of responsibility among providers [5, 19]. Additionally, there were discrepancies between primary care physicians (PCPs) and oncologists regarding survivorship care expectations [3]. Furthermore, systematic factors, including a lack of guidelines for long-term survivor follow-up, lack of reimbursement or a lack of office systems to promote health behavior assessment and counseling [5, 19], all play roles. Previous studies identified problems in communication and a lack of clarity about the respective roles and responsibilities of primary and specialist providers for cancer survivorship planning, which can lead to deficiencies in care [3, 5, 26, 27].

Logistic regression revealed several significant predictors of unmet needs including being female, being employed, having fewer family members, having a long period since initial cancer diagnosis and not receiving chemotherapy. These predictors represent high disease burden (chemotherapy), socioeconomic burden (female, employment and fewer family members) and indifference (long duration after cancer diagnosis). These findings suggest that patients at risk of experiencing unresolved needs must be identified [17], and should be provided with comprehensive individualized care via an SCP based on demographic characteristics, risk assessment and patient choice [3, 5]. SCPs have the greatest potential to facilitate communication and allocation of responsibility between primary care and specialist care [3, 5, 19, 34].

The under-use of cancer surveillance by PCPs may reflect the assumption that an oncologist has remained involved and is leading this aspect of care [5]. Based on a ‘shared care’ model that can facilitate communication and the coordination of care among multiple providers [5, 9, 35], PCPs should encourage patients to make more healthful lifestyle choices. With the implementation of more comprehensive, continuously tailored programs and regularly updated evidence-based practice guidelines [11, 25, 34, 36, 37], patients can take control of their own health scenarios. Information technology may also make important contributions in the area of cost-effectiveness [5].

As this study showed, many cancer survivors still have various unmet needs. Those needs have to be evaluated through structured assessments or unstructured interviews by medical care providers. In 2006, the U.S Institute of Medicine recommended that cancer survivors be provided with a survivorship care plan including, for example, a comprehensive care summary, a follow-up plan for healthy living, and a list of supportive care resources. These survivorship care plans should be designed and supported by a national program [6, 10, 34, 38].

There are important limitations to consider when interpreting the results of this study. One is the low response rate (44.5%), which restricts the generalizability of our findings to similar groups of lung cancer survivors. More severely impaired survivors may have elected not to participate. Second, another limitation was selection bias, which restricts the generalizability of these findings to similar groups of lung cancer survivors. Our study sample may not be representative of the general population of lung cancer survivors, because it was collected at only two academic centers. Third, in this cross-sectional study, we were unable to assess changes in need

<table>
<thead>
<tr>
<th>Table 3. Predictors of items of high unmet need</th>
</tr>
</thead>
<tbody>
<tr>
<td>Need for counseling and treatment for depression and anxiety</td>
</tr>
<tr>
<td>OR</td>
</tr>
<tr>
<td>Married</td>
</tr>
<tr>
<td>Higher education</td>
</tr>
<tr>
<td>Employed</td>
</tr>
<tr>
<td>Higher income</td>
</tr>
<tr>
<td>Lower body mass index</td>
</tr>
<tr>
<td>Did not receive radiotherapy</td>
</tr>
<tr>
<td>Did not receive chemotherapy</td>
</tr>
</tbody>
</table>
according to the length of time since treatment. Further cohort studies are needed to confirm the findings from this study. Fourth, we did not consider overlap when we categorized care needs, but the supportive care needs for pain, fatigue, and appetite loss could overlap those for comorbidity or therapy-related side-effects. Further studies will need to differentiate those needs. Additionally, pain, fatigue, and appetite loss should be separate categories of care, as should the side-effects of therapy.

In conclusion, our study provides evidence that there are substantial unmet needs for CAM information, diet and exercise counseling, psychological support and financial support among lung cancer survivors, especially those with certain risk factors. However, further research is needed to confirm our findings.

funding
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disclosure
The authors have declared no conflicts of interest.

appendix
These are questions about your needs and experiences regarding healthcare services.
After your intensive cancer treatment, did you want to be supported by health providers regarding these healthcare services?

<table>
<thead>
<tr>
<th>The extent of your needs</th>
<th>Not at all</th>
<th>little</th>
<th>Somewhat</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) General information of cancer</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>(2) Explanation regarding the treatment process and prognosis</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>(3) Side-effects caused by cancer treatment (chemotherapy, radiotherapy, etc)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>(4) Fatigue, pain, appetite loss, etc</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>(5) Counseling for anxiety and depression</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>(6) Physical therapy or rehabilitation</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>(7) Counseling for diet (nutrition), exercise and weight control</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>(8) Counseling for smoking secession</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>(9) Complementary and alternative medicine</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>(10) Counseling for family and interpersonal relationships</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>(11) Counseling for genetic issue</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>(12) Counseling for sexual problem</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>(13) Counseling for infertility</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>(14) Cancer screening</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>(15) Co morbidity management</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>(16) Community resources</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>(17) Counseling for insurance</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>(18) Career counseling</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>(19) Financial support</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

references


