

## How do Lung Cancer Patients Experience Stigma?: A Meta-synthesis of Qualitative Studies

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**Purpose:** Lung cancer patients are often stigmatized since lung cancer is closely associated with smoking, which is a self-administered life style. The stigma of lung cancer has been examined in some qualitative studies; however, their findings were diverse and not yet synthesized. Therefore, this meta-synthesis study aimed to explore how lung cancer patients experience stigma. **Methods:** A meta-synthesis method, as suggested by Sandelowski and Barroso in 2007, was applied by aggregating the findings after an evaluation according to consolidated criteria for reporting qualitative research (COREQ). **Results:** By synthesizing the findings of the selected seven papers, a synthesized theme was emerged as “experiencing external and internal distances, which mandates authentic and consistent supports.” The four sub-themes included ‘experiencing some distance from the surrounded world,’ ‘experiencing self-made distance between the disease and oneself,’ ‘the disease experience causes social isolation and loneliness,’ and ‘there is lack of supportive care for myself.’ **Conclusion:** Health care providers should be more attentive to supporting lung cancer patients by providing more effective advocacy programs that improve patients’ quality of life.

**Key Words:** Lung cancer, Stigma, Qualitative study, Meta-synthesis

### INTRODUCTION

Lung cancer was the most common cause of cancer death in South Korea in 2014[1]. Compared to other types of cancer, lung cancer has a higher death rate with regard to incidence. According to a report from the National Cancer Information Center, the incidence of lung cancer was ranked third and fifth in men and women, respectively; however, the death rates of lung cancer in both sexes were all ranked first[1]. The high mortality rate of lung cancer can be explained by the silent symptoms during the early stages; consequently, patients are usually diagnosed at late phase or metastasis stage[2]. Therefore, it is unavoidable that the survival rate for patients with lung cancer is lower than that in patients with other cancers, thereby having the highest death rate. Furthermore, patients with lung cancer present significantly

higher psychological distress and lower quality of life compared to those with other types of cancer[3-7,4]. Since approximately 80% of lung cancer deaths are associated with smoking, which is a self-administered life style choice[8], patients with lung cancer could experience this stigma when diagnosed.

The term “stigma” can be defined as an attribute that discredits certain social relationships [9], including societal attitudes towards the affected groups, institutional stigmatizing practices, actual discrimination experiences, perceived (felt) stigma, and self-referenced stigma. In particular, patients with lung cancer reported much higher levels of perceived stigma than that in patients with other cancers due to the close relationship between lung cancer and smoking[10,4]. Even a recent study[11] found that depressive symptomatology was positively associated with the perceived stigma among patients

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with lung cancer; and the stigma was above and beyond that accounted for by relevant demographic, clinical, and psychosocial factors[11,a4]. Furthermore, with increased awareness about the harmful effects of smoking, as well as passive smoking, smokers acquire public stigmatization acknowledged by health care providers, family, and national press[12]. As a result, this stigmatization of lung cancer and smoking is deeply associated with high levels of depression, blame, guilt, and anxiety among patients with lung cancer by deterring them from seeking proper treatment from health care providers who stigmatize those patients[a4].

There were only four previous studies about stigma related to lung cancer in South Korea, all of which used quantitative methods such as survey. The studies commonly determined that stigma and distress had negative effects on quality of life among lung cancer patients in South Korea[13-16]. However, since those quantitative studies could not rigorously explore patients' lives with this health-related phenomenon[17], qualitative studies were recommended to be conducted in order to properly investigate stigma among patients with lung cancer. It was found that there were no qualitative papers which gave an understanding of life with stigma among lung cancer patients in South Korea; although many qualitative studies about lung cancer and stigma were reported from other countries. Owing to the cultural gap between South Korea and other countries, applying the findings from foreign qualitative studies may not be directly transferable into South Korean settings. Therefore, it is ideal to directly conduct qualitative studies in South Korea. However, it is also crucial to have the essence of the phenomenon from those studies performed in different countries in order to provide fundamental qualitative data to South Korean healthcare, with an integrated sense rather than to implement scattered findings from single studies[18]. A meta-synthesis is a complete and integrated study that involves interpreting, appraising, and analyzing the findings of a number of qualitative studies[18,19]. It is not just a sum of qualitative studies, but also a systematic and scientific synthesis of the findings from the studies followed by new interpretations or a deeper understanding of the subject. Thus, this meta-synthesis study aims to explore how patients with lung cancer experience stigma in order to provide preliminary qualitative data to South Korean settings.

## METHODS

This meta-synthesis was performed in accordance

with the process proposed by Sandelowski and Barroso [19]. The process encompassed identifying a research question, collecting relevant papers, appraising the quality of the studies, and conducting a meta-synthesis.

### 1. Research Question

To identify a research question is the foremost step which gives a clear direction of a meta-synthesis[19]. The question should be broad enough to grab the essential phenomenon that the investigators are interested in [20]. Therefore, the main research question of this study was "How do patients with lung cancer experience stigma?"

### 2. Collecting Relevant Data

#### 1) Search strategy

Systematic searches were performed in four international search engines (EMBASE from 1947 to November 3, 2015, PsycInfo from 1806 to October Week 4 2015, CINAHL, and PubMed) as well as five Korean search engines (RISS, KISS, DBpia, NDSL, and KoreaMed) between October 26, 2015 and November 4, 2015 by the three authors. To increase searching sensitivity, Medical Subject Headings (MeSH) terms were used with all sub-terms and sub-headings by exploding headings. Truncation (i.e., stigma\*) and wildcards (i.e., tumo?r) were also applied when searching for free-text terms. All searching terms were used in combinations with "OR" and "AND"(Table 1).

Inclusion and exclusion criteria were set according to the study aim. Papers were included if they were a qualitative study and written in Korean or English. Studies that used a mixed method design were also screened since they could have qualitative data; however, quantitative studies were excluded because of the study in-

**Table 1. Searching Terms**

"Lung cancer" (MeSH)		
OR		
Lung cancer		
OR		
Pulmonary cancer		
OR		"Stigma" (MeSH)
Lung tumo?r	AND	OR
OR		Stigma*
Pulmonary tumo?r		
OR		
Lung carcinoma		
OR		
Pulmonary carcinoma		

terest. The study population included patients diagnosed with primary lung cancer regardless of the type of lung cancer, treatment period, or other characteristics (i.e., sex, age, and smoking history).

The initial list of search results was scrutinized by two authors (JJ and GJ). After examining the search results by title and abstract, all full-texts of relevant papers were reviewed; if there were any suspicious records, the third author (HS) was consulted to review the papers.

## 2) Search Outcomes

A total 530 papers were found through the systematic searching process (Figure 1). By screening the titles and abstracts of those papers, duplicates and non-primary research papers (n=301) were excluded. The rest of the papers were examined by assessing the titles and abstract with the inclusion criteria described above; then unsuitable records were eliminated (n=207). After reviewing the remaining papers (n=22) in full-text, 15 papers were excluded: no qualitative data (n=4), review paper (n=2), different population (n=4), online data analysis (n=2), duplicate with different title (n=1), and non-lung cancer (n=2). Finally, a total seven papers were selected that fully met the inclusion criteria.

The seven selected papers were all written in English, as there were no qualitative studies published in Korean with the same topic. The studies were conducted in the U.S.(n=3), U.K.(n=3), and Australia (n=1) between 2002 and 2014. A total of 168 patients with lung cancer were included. As per Table 2, the aims, analysis methods,

and findings of the studies were very diverse. Although there was heterogeneous data, the differences could be addressed by comparability work[21] such as the process of identifying a problem, setting inclusion criteria, selecting search terms and sources, and extracting data [21]. As a result, the comparability work enabled this meta-synthesis paper to be transparent and reproducible, which allowed a comparison of the differences.

## 3. Quality Appraisal

Appraisal of the selected studies was performed in accordance with Criteria for Reporting Qualitative Research (COREQ) developed by Tong et al.,[22]. The COREQ helps researchers to evaluate the quality of qualitative papers in three main domains:(1) research team and reflexivity,(2) study design, and (3) analysis and findings.

All selected studies were initially assessed by JJ and GJ individually; then, a consensus was made through discussion in order to enhance reliability. The result of this assessment was illustrated in Table 3.

## 4. Meta-synthesis

When synthesizing the findings of the selected papers, the meta-aggregative approach developed by the Joanna Briggs Institute (JBI)[23] was mainly applied. This approach is a detailed and specified methodology which seeks to move beyond the implicit suggestions from primary findings of research papers[23]. It entails

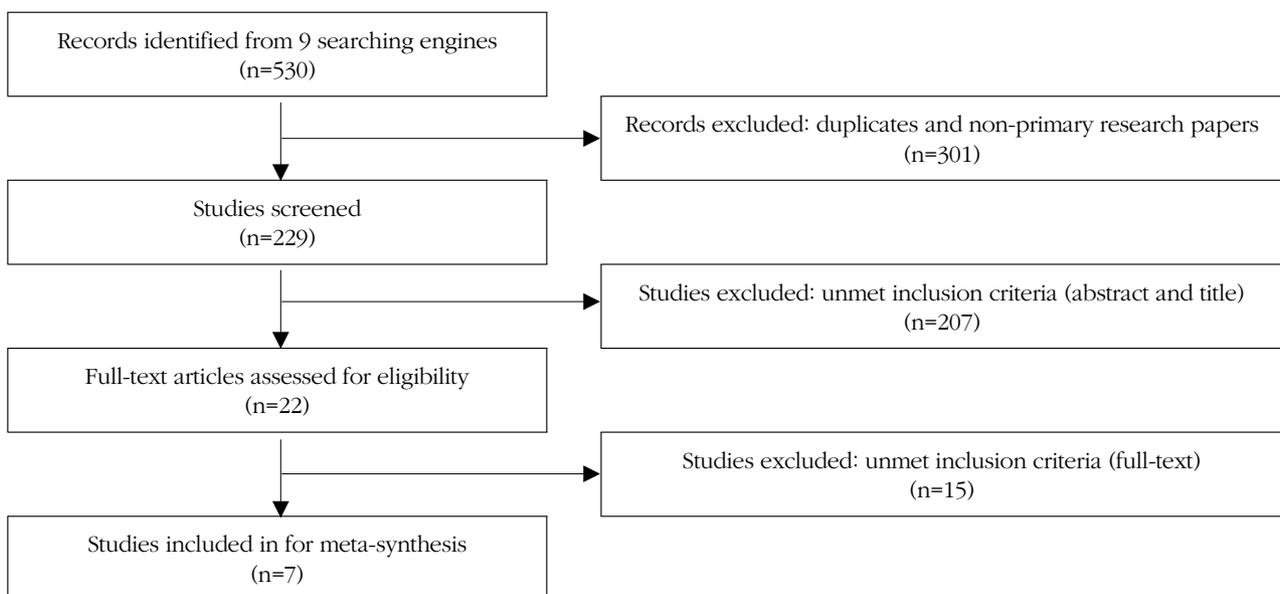


Figure 1. Flowchart of the search process.

**Table 2.** Summary of the Included Studies

Author (year)	Title	Nation	Method	Analysis method	Participants	Findings
Brown & Cataldo (2013)	Explorations of lung cancer stigma for female long-term survivors	USA	One-on-one and group interview	Gee's discourse analysis methodology, Fairclough's critical discourse theory, integrates thematic analysis, linguistic analysis, discourse analysis and critical discourse analysis	N=8	<ul style="list-style-type: none"> <li>Unvoiced precursors-tobacco industry and addiction influence</li> <li>Perception of LCS-diagnosis and interaction with healthcare providers</li> <li>Perception of stigma-shifting entities</li> <li>Responses to stigma-information control, advocacy</li> <li>Conflicting responses to stigma-simultaneous rejection and assumption of stigma</li> </ul>
Chapple et al (2004)	Stigma, shame, and blame experienced by patients with lung cancer qualitative study	United Kingdom	Narrative interview	Not mentioned	N=45	<ul style="list-style-type: none"> <li>Patient's experience and fear of stigma</li> <li>Resistance to blame and stigmatization</li> <li>Fear about lack of access to medical care</li> </ul>
Hamann et al (2014)	Stigma among patients with lung cancer: A patient-reported measurement model	USA	Semi-structured interviews and focus groups	Thematic analysis	<ul style="list-style-type: none"> <li>Interview group (n=42)</li> <li>Five focus groups (n=23)</li> </ul>	<ul style="list-style-type: none"> <li>Perceived/felt stigma</li> <li>Internalized stigma: self-blame, guilt, shame, anger, regret</li> <li>Consequences</li> </ul>
Lehto (2014)	Patient views on smoking, lung cancer, and stigma: A focus group perspective	USA	A focus group	Thematic analysis	<ul style="list-style-type: none"> <li>Four focus groups (n=11)</li> </ul>	<ul style="list-style-type: none"> <li>Societal attitudes</li> <li>Institutional practices and experiences</li> <li>Negative thoughts and emotions</li> <li>Actual stigmatization experiences</li> <li>Smoking cessation: personal choice versus addiction</li> <li>Causal attributions</li> </ul>
Rowland et al (2014)	Quality of life, support and smoking in advanced lung cancer patients: a qualitative study	United Kingdom	Semi-structured interviews	Interpretative phenomenological analysis	N=9	<ul style="list-style-type: none"> <li>Effects of illness on quality of life</li> <li>Family support</li> <li>Coping strategies</li> <li>Medical support</li> <li>Smoking</li> </ul>
Scott et al (2015)	Stigma as a barrier to diagnosis of lung cancer: patient and general practitioner perspectives	Australia	Semi-structured in-depth interview	Thematic analysis	<ul style="list-style-type: none"> <li>N=20</li> <li>Patient (n=10), GP (n=10)</li> </ul>	<ul style="list-style-type: none"> <li>Experience of blame and stigma</li> <li>GPs preconceptions of lung cancer risk</li> <li>Anti-smoking messaging</li> </ul>
Tod et al (2008)	Diagnostic delay in lung cancer	United Kingdom	Semi-structured individual interviews	Framework analysis	N=20	<ul style="list-style-type: none"> <li>Symptom experience</li> <li>Knowledge</li> <li>Fear</li> <li>Blame and stigma</li> <li>Culture</li> </ul>

extracting, categorizing, and synthesizing the themes from the selected papers.

First, all findings from the chosen papers were extracted and gathered by the authors (JJ and GJ). As JBI recommended, the authors tried to ensure the findings remained as close to the original stance as possible. Second, those findings were categorized after evaluating the similarity in meaning of the findings. Finally, a com-

prehensive set of synthesized findings was produced.

## RESULTS

During the meta-aggregation process, total 53 findings were extracted by the authors from the selected papers. Those findings were identified as 8 categories; then, 4 sub-themes were categorized. Finally, a synthe-

**Table 3.** Quality Appraisal Tool (COREQ)

Item	a1	a2	a3	a4	a5	a6	a7
Domain 1: Research team and reflexivity							
1. Interviewer/Facilitator Which author/s conducted the interview or focus group?	nc	✓	nc	✓	nc	nc	✓
2. Credentials What were the researcher's credentials?	✓	✓	nc	✓	✓	X	✓
3. Occupations What was their occupation at the time of the study?	✓	✓	✓	✓	nc	✓	✓
4. Gender Was the researcher male or female?	nc						
5. Experience and training What experience or training did the researcher have?	nc	nc	✓	✓	X	nc	X
6. Relationship established Was a relationship established prior to study commencement?	X	X	✓	✓	X	X	X
7. Participant knowledge of interviewer What did the participants know about the researcher?	X	X	✓	✓	X	X	X
8. Interviewer characteristics What characteristics were reported about the interviewer/facilitator?	X	✓	✓	✓	X	nc	X
Domain 2: Study design							
9. Methodological orientation and Theory What methodological orientation was stated to underpin the study?	✓	X	✓	v	✓	✓	✓
10. Sampling How were participants selected?	✓	✓	✓	✓	✓	✓	✓
11. Method of approach How were participants approached?	✓	✓	✓	✓	✓	✓	✓
12. Sample size How many participants were in study?	✓	✓	✓	✓	✓	✓	✓
13. Non-participation How many people refused to participate or dropped out? Reasons?	X	X	✓	✓	✓	X	X
14. Setting of data collection Where was the data collected?	nc	✓	✓	✓	✓	X	✓
15. Presence of non-participants Was anyone else present besides the participants and researchers?	X	X	✓	X	X	X	✓
16. Description of sample What are the important characteristics of the sample?	✓	✓	✓	✓	✓	nc	✓
17. Interview guide Were questions, prompts, guides provided by the authors? Was it pilot tested?	✓	X	✓	X	✓	X	X
18. Repeat Interviews Were repeat interviews carried out? If yes, how many?	X	X	X	X	X	X	X
19. Audio/visual recording Did the research use audio or visual recording to collect the data?	✓	✓	✓	✓	✓	✓	✓
20. Field notes Were field notes made during and/or after the interview or focus group?	X	X	X	X	X	X	✓
21. Duration What was the duration of the interviews or focus group?	✓	✓	X	nc	✓	X	✓
22. Data saturation Was data saturation discussed?	X	✓	✓	X	✓	X	X
23. Transcripts returned Were transcripts returned to participants for comment and/or correction?	X	✓	X	X	X	X	X
Domain 3: Analysis and findings							
24. Number of data coders How many data coders coded the data?	X	✓	✓	✓	✓	X	✓
25. Description of the coding tree Did authors provide a description of the coding tree?	X	X	nc	X	✓	X	X
26. Derivation of themes Were themes identified in advance or derived from the data?	✓	✓	✓	✓	✓	✓	✓
27. Software What software, if applicable, was used to manage the data?	X	✓	✓	X	X	✓	✓
28. Participant checking Did participants provide feedback on the findings?	X	X	✓	X	X	X	X
29. Quotations presented Were participant quotations presented to illustrate the themes/findings?	✓	✓	✓	✓	✓	✓	✓
30. Data and findings consistent Was there consistency between the data presented and the findings?	✓	✓	✓	✓	✓	✓	✓
31. Clarity of major themes Were major themes clearly presented in the findings?	✓	✓	✓	✓	✓	✓	✓
32. Clarity of minor themes Is there a description of diverse cases or discussion of minor themes?	nc	nc	✓	✓	✓	nc	nc

Key: ✓=Information was provided and described; X=Information was not provided; nc=Information was not clear or sufficient.

sized theme “experiencing external and internal distances, which mandates authentic and consistent supports” was emerged (Table 4).

**Synthesized Theme**

By synthesizing those findings, the comprehensive theme was found as “experiencing external and internal distances, which mandates authentic and consistent supports.” The first phrase of ‘experiencing external and internal distances’ is elicited from the following two sub-themes: ‘experiencing some distance from the surrounded world,’ and ‘experiencing self-made distance between the disease and oneself.’ In addition, the latter part of the final theme, ‘it mandates authentic and consistent supports,’ is demonstrated within two sub-themes, ‘the disease experience causes social isolation and loneliness,’ and ‘there is lack of supportive care for myself.’ Aforementioned four sub-themes are described as follows.

**1. Experiencing Some Distance from the Surrounded World**

**1) Perceived stigma by public**

Perceived stigma can be defined as the thoughts or beliefs of most people about the stigmatized group in general[24]. Some patients with lung cancer experienced perceived stigma by the public because they were smokers (self-inflicted) or were assumed to be even if they never smoked[a1-a7]. In particular, anti-smoking campaigns from television advertisements and tobacco packaging warning messages were closely related to public stigmatization[a2,a5,a6]. Since these campaigns and messages focus on increasing awareness about the

importance of anti-smoking, the negative effects of smoking were excessively highlighted; consequently, patients with lung cancer were perceived as a group of people who have a “self-inflicted disease”[a2]. Not only smokers, but also non-smoking patients felt stigmatized since public opinion associates patients with lung cancer with smoking, which could be attributed to biased anti-smoking advertisements that portray a relationship between lung cancer and smoking[a2,a5,a6].

**2) Perceived stigma by family and friends**

Patients with lung cancer in both smoking and non-smoking groups had negative appraisal and devaluation from family and friends who had knowledge about the patient’s lung cancer diagnosis[a2,a3,a5]. Although we found a case of a positive reaction towards patients with lung cancer[a5] by contacting the patients more frequently than before, negative reactions, such as avoiding contact, outweighed the positive reactions in many cases [a2,a3,a5]. Avoidance among family and friends was reported in relation to several factors: the negative images of lung cancer (e.g., a horrible death), symptoms like “gasping for air,” embarrassment (felt dirtied), and not knowing what to say[a2,a4,a5].

**3) Perceived stigma by health care providers**

Some patients with lung cancer reported that they experienced uncomfortable interactions with health care providers[a1-a6]. Some medical staff possessed smoking-related stigma [a1,a2-a4,a6] by showing unsuitable verbal expressions towards patients[a1-a3]. Indeed, most patients with lung cancer without a history of smoking even received smoking-related assumptions from health care providers[a2], “The doctor will almost certainly say to you, ‘Do you smoke?’” This stigmatization from me-

**Table 4. Meta-aggregation Process**

Findings (Extraction)	Categories (Categorization)	Sub-themes (Categorization)	Synthesis (Synthesization)
53 findings from 7 papers	Perceived stigma by public Perceived stigma by family and friends Perceived stigma by health care providers	Experiencing some distance from the surrounded world	Experiencing external and internal distances, which mandates authentic and consistent supports
	Blame, guilt, shame, and frustration Regret, anger, and fear Shifting of identities	Experiencing self-made distance between the disease and oneself	
	Social isolation and loneliness	The disease experience causes social isolation and loneliness	
	Lack of supportive care	There is lack of supportive care for myself	

dical staff was also linked with unsuitable verbal expressions such as the epistemic “must” construction that was used in conversation when health care providers met patients; *“Your immune system must be messed up”*[a1].

## 2. Experiencing Self-made Distance between the Disease and Oneself

### 1) Internalized stigma: blame, guilt, shame and frustration

Stigma can also be identified by internalization of the stigma by others (i.e. general public, friend, family, health providers)[25]. The product of internalized stigma encompasses shame, blame, hopelessness, guilt, and fear of discrimination associated with mental illness[26].

Most lung cancer patients felt negative emotions such as blame, shame, guilt, and frustration[a1,a2-a4,a6,a7]. Self-blame was associated with self-deprecation in relation to smoking among some patients who have a history of smoking; *“I blame myself... it is my fault”*[a4]. Interestingly, older people tended to be less self-blaming for having lung cancer compared to younger people since they were addicted when smoking was socially accepted, before smoking harms were widely known[a2]. Self-blame and guilt [a2,a3,a4,a6,a7] were often manifested among patients, regardless of smoking status, in relation to smoking and family impact; *“I feel guilty about it, in regards to the burden it’s put on [my family]... as a smoker, a risk taker, I failed to think of the risks”*[a3]. Moreover, it was found that smoking-related guilt and severe depression were also associated[a4].

The emotional expression “shame”[a2,a3] was not often used by patients in the selected studies; however, a participant felt deeply ashamed because as a patient with lung cancer, the patient was not able to support the family as before[a2]. Another patient also described “shame” in a mixed emotional expression; *“So I felt all those thoughts, the guilt, shame, anger, regret, all those”* [a3].

Frustration [a1,a4] was identified when the patients described about the emotion that is related to loss of a career; *“It’s frustrating.. I can’t continue with the career”*[a1]; and how their family members reacted to a diagnosis associated with smoking; *“My mom went up to them and said, ‘my daughter was just diagnosed with cancer please stop smoking’.”*[a4].

### 2) Internalized stigma: regret, anger and fear

Negative thoughts and feelings associated with having lung cancer were also expressed as regret, anger,

and fear among the patients. Regret[a3,a4] was closely related to smoking history; *“It wouldn’t do any good because I have smoked for that many years”* [a3]; *“I wish I had done that different”*[a4].

Some participants expressed “anger”[a1-a5] at both themselves and others. For example, a participant reported that he was not able to control his anger when he was with his wife; *“I started getting nasty with her... I just got bad... why should I put them through all of this?”*[a4]. In addition, some smokers or ex-smokers upset over tobacco industry, government, or anti-smoking legislation; *“It’s not our fault, it’s the tobacco manufacturers’ fault for putting the carcinogen”*[a2]; *“Why in the world are they allowing the tobacco companies to continue without being fined? I’m very angry about our government letting this continue”* [a3]; *“I hate those adverts”*[a2].

The emotion “fear” for being a lung cancer patient was also associated with the anti-smoking adverts, causing delays in diagnosis[a6]; since lung cancer patients who were smokers knew the relationship between smoking and lung cancer, they were hesitant to seek medical support for symptoms that had the potential to be lung cancer. Moreover, fear of being stigmatized was also described in a participant’s story who had epilepsy and experienced stigma already; *“I was diagnosed as having epilepsy... that was catching to everyone and stopped her children seeing my children very abruptly... It really made me feel very uncomfortable”*[a2].

### 3) Shifting of identities

The patients with lung cancer perceived their identities in various forms [a1-a7] including patient with lung cancer, smoker or non-smoker, and mother or father. In particular, it was notable that almost all patients with lung cancer mainly defined themselves as either a smoker or non-smoker. In particular, when the non-smokers described themselves, they used the words such as “normal people” or “victim” in order to keep themselves from the smoking-related stigma; *“I think sharing is important to make people aware that normal people who weren’t smokers... do get lung cancer”*[a1].

## 3. The Disease Experience Causes Social Isolation and Loneliness

Most patients with lung cancer experienced feelings of isolation [a1,a2,a4,a5] from social support groups and having lack of advocacy[a1-a4,a6,a7]. Isolation from social support groups among lung cancer patients was

found in most of the selected papers[a1-a5]. Social isolation can be measured in an objective manner by using observations of a person's social interactions, while loneliness can be measured in a subjective manner by seeking the questions about relationships, social activity, and feelings about social activity[27]. Both terms isolation and loneliness are usually interchangeable in layman's term; as a result, most patients described their lives as "isolated" rather than "lonely." The patients tended to be isolated by either themselves or others (public or family) because of the lung cancer related stigma described above. A patient described self-isolation as her response to stigmatization; *"Just becoming isolated from everybody"*[a1]. This isolation was often described in patients' talks by comparing lung cancer to a communicable disease such as leprosy although lung cancer is a not contagious disease[a2,a3]; *"leper"*[a2]; *"Some of my friends sort of moved away like I had the leprosy"* [a3].

#### 4. There is a Lack of Supportive Care for Myself

Many participants reported more discrimination against lung cancer compared to other common cancers [a2-a4, a6,a7] such as breast cancer; *"If you compare the amount of money that's allocated to breast cancer for research and screening programs... with that those of lung cancer, there is a huge difference"*[a2]. This discrimination was reported to make patients feel more stigmatized since lung cancer was considered a self-inflicted disease undeserving of help[a2,a3,a6].

Interestingly, one patient with lung cancer mentioned a negative experience about an advocacy program for lung cancer patients. The lung cancer advocacy foundation she joined was intended to build a new "face of lung cancer" among that public about atypical patients such as young people and non-smokers. However, the participant reported feeling excluded and even more stigmatized because she was very close to a non-atypical patient: *"sixty-year-old and ex-smoker"*[a1].

## DISCUSSION

This meta-synthesis study explored the experiences of lung cancer patients with stigma by integrating the findings of seven qualitative studies with 168 patients. The main theme, 'experiencing external and internal distances, which mandates authentic and consistent supports' was identified by the meta-aggregative approach. The findings clarify the need for authentic and con-

sistent social supports for patients with lung cancer and highlight the hidden area in oncology nursing care. Additionally, this study also contributes to the few preceding studies that raise the issue of stigma against patients with lung cancer in South Korea.

Recently, scholars have become increasingly aware about the lack of support for lung cancer patients. Weiss et al.,[28] performed a telephone survey in the U.S. showing only 8% of participants were involved with lung cancer organizations, while support involvement for breast cancer was the greatest among all cancer types with 18% participation. The authors also pointed out that stigmatization of lung cancer might have influenced this poor level of support. Moreover, the national survey from South Korea conducted by Cho et al.,[15] found that people who were never diagnosed cancer would avoid working with co-workers who have cancer. It can be seen that this avoidance of being in contact with patients with cancer represents negative public attitudes towards cancer patients: stigmatization.

In addition, a recent meta-synthesis by Suh[29] ascertained the impact of cancer diagnosis and its treatment on Korean women's lives by synthesizing 21 qualitative studies. Three main themes were identified: spaced-out from the usualness, mindfulness on profound desires, and redefinition of every relation. Although this meta-synthesis study included only female cancer patients, the findings indicated the importance of social support for cancer patients.

We found no meta-synthesis paper about lung cancer and stigma-related topics. Therefore, one of the strengths of this paper is that it is the first meta-synthesis study to provide integrated findings of existing papers in reference to stigma on lung cancer. Although we found several single papers with similar study aims, the findings were scattered. As a result, the synthesized findings of this paper can give a holistic view to understand and gain knowledge about how the patients with lung cancer experience stigma. Moreover, the theme "mandates authentic and consistent supports" was found through the synthesizing process. By introducing this theme, it was possible to highlight this unrecognized issue among lung cancer patients. In particular, in oncology nursing practice, the rationale for setting advocacy groups for lung cancer patients can be justified by the findings of this study. In addition, the use of COREQ[22] enabled this study to have more credible findings by taking into account the important aspects of qualitative studies, evaluating the papers by the authors (JJ and GJ).

In terms of limitations, this study contains heteroge-

neous populations and settings. More specifically, the selected studies synthesized have different proportions of sex, ages, lung cancer stages, and cultures. Additionally, two studies[a2,a4] did not mention important characteristics of lung cancer patients such as smoking history and types of lung cancer. However, it was accepted because one of the strengths of a qualitative study is to collect data in a naturalistic setting with few controlled variables; therefore, each case is identified unique and less amenable to generalization, but having transferability[30]. Nonetheless, those heterogeneous characteristics have made the findings too diversified from seven different papers. In order to collect more representative qualitative data, specified population selection criteria including sex, age, type of lung cancer, and smoking history should be considered when recruiting participants. Additionally, this study merely synthesized studies from the U.S., U.K., and Australia. Thus, to rigorously understand the experience of lung cancer patients with stigma in South Korea, single qualitative studies within South Korean settings should be performed and synthesized once the data is available.

When it comes to implications for practice, health care providers should be more concerned about the stigma of lung cancer by not assuming a patient is a smoker, and by supporting effective advocacy programs. For instance, historically breast cancer was once highly stigmatized and hardly known to the public; however, by the aids from breast cancer supporters who bore pink ribbons, breast cancer began to be openly discussed in public by increasing awareness. Consequently, more funding and volunteerism were generated; subsequently breast cancer patients now suffer from less stigma[28]. Likewise, more advocacy activities should be promoted in order to reduce burden of suffering from lung cancer.

The biased statements of anti-smoking advertisements should also be modified as lung cancer patients experience more stigmatized feelings from them; *“They [anti-smoking ads] are actually harming every single lung cancer patient that is fighting this disease”[a6]*. Furthermore, through the searching process, it was revealed that there were no qualitative studies conducted in South Korea about lung cancer and stigma-related issues. To understand and consider the patients’ lives in a holistic view, qualitative studies should be encouraged.

## CONCLUSION

The experiences of lung cancer patients with stigma were explored in this study. The synthesized results of

the selected studies revealed that patients with lung cancer experienced external and internal distances, which mandated authentic and consistent supports. The perceived stigmas by public, family, and health care providers were felt as if they had some distance from the world. The internalized stigma resulted in shifting of identity. In addition, an obvious experience of being isolated among the lung cancer patients with insufficient advocacy revealed the needs for authentic and consistent support for them. The findings of the present study suggest that health care providers should be more attentive to supporting patients with lung cancer by providing more effective support programs in order to reduce stigma and improve quality of life.

## REFERENCES

1. Korea Central Cancer Registry. National cancer statistics in 2014. Goyang-si, Gyeonggi-do: National Cancer Information Center; 2014 [cited 2015 September 25]. Available from: [http://www.cancer.go.kr/mbs/cancer/subview.jsp?id=cancer\\_040201000000](http://www.cancer.go.kr/mbs/cancer/subview.jsp?id=cancer_040201000000)
2. Chatwin J, Sanders C. The influence of social factors on help-seeking for people with lung cancer. *European Journal of Cancer Care*. 2013;22(6):709-13. <http://dx.doi.org/10.1111/ecc.12078>
3. Schag C, Ganz P, Wing D, Sim MS, Lee J. Quality of life in adult survivors of lung, colon and prostate cancer. *Quality of Life Research*. 1994;3(2):127-41.
4. Sikorskii A, Given CW, Given B, Jeon S, Decker V, Decker D, et al. Symptom management for cancer patients: a trial comparing two multimodal interventions. *Journal of Pain and Symptom Management*. 2007;34(3):253-64. <http://dx.doi.org/10.1016/j.jpainsymman.2006.11.018>
5. Sarna L, Evangelista L, Tashkin D, Padilla G, Holmes C, Brecht ML, et al. Impact of respiratory symptoms and pulmonary function on quality of life of long-term survivors of non-small cell lung cancer. *Chest*. 2004;125(2):439-45. <http://dx.doi.org/10.1378/chest.125.2.439>
6. Zabora J, BrintzenhofeSzoc K, Curbow B, Hooker C, Piantadosi S. The prevalence of psychological distress by cancer site. *Psycho-Oncology*. 2001;10(1):19-28.
7. Hill KM, Amir Z, Muers MF, Connolly CK, Round CE. Do newly diagnosed lung cancer patients feel their concerns are being met? *European Journal of Cancer Care*. 2003;12(1):35-45. <http://dx.doi.org/10.1046/j.1365-2354.2003.00324.x>
8. American Cancer Society. *Cancer Facts & Figures 2012*. Atlanta GA: American Cancer Society; 2012 [cited 2015 December 18]. Available from: <http://www.cancer.org/acs/groups/content/@epidemiology>

- surveillance/documents/document/acspc-031941.pdf
9. Goffman E. Stigma: notes on the management of spoiled identity. Cliffs E, editor. New Jersey: Prentice Hall; 1963.
  10. LoConte NK, Else-Quest NM, Eickhoff J, Hyde J, Schiller JH. Assessment of guilt and shame in patients with non-small-cell lung cancer compared with patients with breast and prostate cancer. *Clinical lung cancer*. 2008;9(3):171-8. <http://dx.doi.org/10.3816/CLC.2008.n.026>
  11. Gonzalez BD, Jacobsen PB. Depression in lung cancer patients: the role of perceived stigma. *Psycho-Oncology*. 2012;21(3):239-46. <http://dx.doi.org/10.1002/pon.1882>
  12. Conlon A, Gilbert D, Jones B, Aldredge P. Stacked stigma: oncology social workers' perceptions of the lung cancer experience. *Journal of Psychosocial Oncology*. 2010;28(1):98-115. <http://dx.doi.org/10.1080/07347330903438982>
  13. Lee JL, Kim KS. The Relationships between stigma, distress, and quality of life in patients with lung cancer. *Asian Oncology Nursing*. 2011;11(3):237-46. <http://dx.doi.org/10.5388/jkon.2011.11.3.237>
  14. Byun HS, Kim EK, Kim GD. Impacts of stigma and distress on the quality of Life in patients with lung cancer. *Journal of safety and crisis management*. 2015;11(8):223-40.
  15. Cho J, Smith K, Choi EK, Kim IR, Chang YJ, Park HY, et al. Public attitudes toward cancer and cancer patients: a national survey in Korea. *Psycho-Oncology*. 2013;22(3):605-13. <http://dx.doi.org/10.1002/pon.3041>
  16. Kim MA, Yi J. Life after cancer: How does public stigma increase psychological distress of childhood cancer survivors? *International journal of nursing studies*. 2014;51(12):1605-14. <http://dx.doi.org/10.1016/j.ijnurstu.2014.04.005>.
  17. Bowling A. *Research methods in health: investigating health and health services*: McGraw-Hill Education (UK); 2014.
  18. Jensen LA, Allen MN. Meta-synthesis of qualitative findings. *Qualitative Health Research*. 1996;6(4):553-60.
  19. Sandelowski M, Barroso J. *Handbook for synthesizing qualitative research*. Springer Publishing Company; 2007.
  20. Finfgeld DL. Metasynthesis: the state of the art-so far. *Qualitative Health Research*. 2003;13(7):893-904. <http://dx.doi.org/10.1177/1049732303253462>
  21. Sandelowski M, Voils CI, Barroso J. Comparability work and the management of difference in research synthesis studies. *Social Science & Medicine*. 2007;64(1):236-47. <http://dx.doi.org/10.1016/j.socscimed.2006.08.041>
  22. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007;19(6):349-57.
  23. Joanna Briggs Institute. *Joanna Briggs Institute reviewers' manual 2014: methodology for JBI umbrella reviews*. Australia: Joanna Briggs Institute; 2014 [cited 2015 December 23]. Available from: [http://joannabriggs.org/assets/docs/sumari/ReviewersManual-Methodology-JBI\\_Umbrella%20Reviews-2014.pdf](http://joannabriggs.org/assets/docs/sumari/ReviewersManual-Methodology-JBI_Umbrella%20Reviews-2014.pdf)
  24. LeBel TP. Perceptions of and responses to stigma. *Sociology Compass*. 2008;2(2):409-32. <http://dx.doi.org/10.1111/j.1751-9020.2007.00081.x>
  25. Corrigan PW, Watson AC. The paradox of self-stigma and mental illness. *Clinical Psychology: Science and Practice*. 2002; 9(1):35-53. <http://dx.doi.org/10.1093/clipsy.9.1.35>
  26. Corrigan PW. The impact of stigma on severe mental illness. *Cognitive and Behavioral Practice*. 1999;5(2):201-22. [http://dx.doi.org/10.1016/S1077-7229\(98\)80006-0](http://dx.doi.org/10.1016/S1077-7229(98)80006-0)
  27. British Columbia Ministry of Health. *Social isolation of seniors: an emerging issues*. Children's, Women's and Seniors Health Branch, Canada: Ministry of Health; 2004 [cited 2015 December 22]. Available from: [http://www.health.gov.bc.ca/library/publications/year/2004/Social\\_Isolation\\_Among\\_Seniors.pdf](http://www.health.gov.bc.ca/library/publications/year/2004/Social_Isolation_Among_Seniors.pdf)
  28. Weiss J, Stephenson BJ, Edwards LJ, Rigney M, Copeland A. Public attitudes about lung cancer: stigma, support, and predictors of support. *Journal of Multidisciplinary Healthcare*. 2014;7:293-300. <http://dx.doi.org/10.2147/JMDH.S65153>
  29. Suh EE. The impact of cancer diagnosis and its treatment on Korean women's lives: a meta-synthesis study. *Korean Journal of Adult Nursing*. 2015;27(1):117-26. <http://dx.doi.org/10.7475/kjan.2015.27.1.117>
  30. Krefting L. Rigor in qualitative research: the assessment of trustworthiness. *American Journal of Occupational Therapy*. 1991; 45(3):214-22.

## Appendix

- a1. Brown C, Cataldo J. Explorations of lung cancer stigma for female long-term survivors. *Nursing Inquiry*. 2013;20(4):352-62. <http://dx.doi.org/10.1111/nin.12024>
- a2. Chapple A, Ziebland S, McPherson A. Stigma, shame, and blame experienced by patients with lung cancer: Qualitative study. *British Medical Journal*. 2004;328 (7454):1470-3. <http://dx.doi.org/10.1136/bmj.38111.639734.7C>
- a3. Hamann HA, Ostroff JS, Marks EG, Gerber DE, Schiller JH, Lee SJ. Stigma among patients with lung cancer: a patient-reported measurement model. *Psycho-Oncology*. 2014;23(1):81-92. <http://dx.doi.org/10.1002/pon.3371>
- a4. Lehto RH. Patient views on smoking, lung cancer, and stigma: a focus group perspective. *European Journal of Oncology Nursing: The Official Journal of European Oncology Nursing Society*. 2014;18(3):316-22. <http://dx.doi.org/10.1016/j.ejon.2014.02.003>
- a5. Rowland C, Danson S, Rowe R, Merrick H, Woll P, Hatton M, et al. Quality of life, support and smoking in advanced lung cancer patients: a qualitative study. *BMJ supportive & palliative care*. 2014:1-8. <http://dx.doi.org/10.1136/bmjspcare-2013-000589>
- a6. Scott N, Crane M, Lafontaine M, Seale H, Currow D. Stigma as a barrier to diagnosis of lung cancer: Patient and general practitioner perspectives. *Primary Health Care Research and Development*. 2015:1-5. <http://dx.doi.org/10.1017/S1463423615000043>
- a7. Tod AM, Craven J, Allmark P. Diagnostic delay in lung cancer: a qualitative study. *Journal of Advanced Nursing*. 2008;61(3):336-43. <http://dx.doi.org/10.1111/j.1365-2648.2007.04542.x>