# Guilt, censure, and concealment of active smoking status among cancer patients and family members after diagnosis: a nationwide study

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#### Abstract

*Objectives*: We aimed to identify the prevalence of feelings of guilt, censure, and concealment of smoking status among cancer patients and their family members who continued to smoke after the patient's diagnosis.

*Methods*: Among 990 patient-family member dyads, 45 patients and 173 family members who continued to smoke for at least 1 month after the patients' diagnoses were administered questions examining feelings of guilt, censure, and smoking concealment.

*Results*: Most patients who continued to smoke reported experiencing feelings of guilt toward their families (75.6%) and censure from their family members (77.8%), and many concealed their smoking from their family members (44.4%) or healthcare professionals (46.7%). Family members who continued to smoke also reported feelings of guilt with respect to the patient (63.6%) and that the patient was critical of them (68.9%), and many concealed their smoking from the patient (28.5%) or healthcare professionals (9.3%). Patients' feeling of guilt was associated with concealment of smoking from family members (55.9% vs. 10.0%) or health care professionals (55.9% vs. 20.0%). Family members who reported feeling guilty (36.5% vs. 16.3%) or censured (34.5% vs. 16.7%) were more likely to conceal smoking from patients.

*Conclusion*: Many patients and family members continue to smoke following cancer diagnosis, and the majority of them experience feelings of guilt and censure, which can lead to the concealment of smoking status from families or health care professionals. Feelings of guilt, censure, and concealment of smoking should be considered in the development and implementation of smoking cessation programs for cancer patients and family members.

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# Introduction

Given the increased awareness of the health risks caused by smoking as well as the introduction of active tobacco control policies, smoking has become increasingly socially unacceptable and non-normative [1,2]. Although tobacco control strategies promoting the message that 'smoking causes cancer' have effectively contributed to reduce smoking rates, this message has also contributed to the stigmatization of smokers, which has untoward consequences [3] such as feelings of guilt and censure and concealment of smoking from families [4] and healthcare professionals (HCPs) [5]. This could be problematic, because family support is a strong predictor of smoking cessation [6,7], and HCPs are in the best position to help smokers to quit.

Smoking is a major cause of a variety of cancers. Therefore, cancer patients who smoke are likely to be at higher risk for feelings of guilt and censure, which are negative consequences of stigmatization [8]. Smoking is also an issue for family members of cancer patients, as it has been estimated that every person diagnosed with cancer has two relatives who smoke [9]. A family member who smokes may feel responsible for causing a patient's cancer or even face blame from the patient [10,11].

Given that perceived social and emotional support within the family are important determinants of smoking cessation in a cancer care setting [12,13]; it is important to understand the family dynamics that influence smoking behaviors in cancer patients and their family members [14]. However, to date, little attention has been directed toward this issue, and most previous studies have been qualitative evaluations of selective samples [10,11,14,15], focusing particularly on lung cancer patients and their family members [10,11,14–19]. Furthermore, feelings of guilt and concealment of smoking status by family members have seldom been addressed.

A better understanding of the effects of a diagnosis of cancer on family dynamics and interaction in a family context could help to guide the development of tailored smoking-cessation interventions for cancer patients and their families [14]. Therefore, the purpose of this study was the following: (i) to identify the prevalence of guilt, censure, and concealment of smoking status among a wide range of cancer patients and their family members who continued smoking after a diagnosis of cancer and (ii) to examine the association of concealment of smoking with feelings of guilt and censure.

### Methods

#### Study subjects and procedures

This study was conducted as part of Cancer Patient Experience Study, which is an annual nationwide survey of cancer patient experience in Korea. In 2011, the study was conducted with patient–family member dyads, to explore medical care and treatment views of cancer patients and family members [20]. In this particular study, we sought to determine the prevalence of feelings of guilt, censure, and concealment of smoking status among cancer patients and their family members who continued to smoke after the patient's diagnosis. The National Cancer Center and nine government-designated Regional Cancer Centers in Korea participated in the survey. The study was approved by the institutional review board of the National Cancer Center, Korea.

Patients accompanied by family members in outpatient waiting areas or in inpatient wards were consecutively recruited by study interviewers, who explained the Cancer Patient Experience survey purpose and procedures. Quota sampling methods was used to make the sample be representative of geographic area and cancer types. Inclusion criteria for patients were the following: over 18 years of age, a diagnosis of cancer, currently receiving cancer treatment or follow-up care, and in sufficiently good physical and mental health to complete the study questionnaire. Accompanying family members needed to be over 18 years of age to be included. Patient-family member dyads were enrolled when both the patient and the family member agreed to participate. We approached 1299 dyads and enrolled 990 (participation rate = 76.2%). A total of 188 patients and 173 family members who were

smoking at the time of diagnosis were included for the analyses in this particular study.

Consenting patients and their family members were instructed to complete the study questionnaires independently in a separate area to avoid consultation or sharing of information. Medical baseline data including primary cancer diagnosis, Surveillance, Epidemiology, and End Results stage, and the time since cancer diagnosis were retrieved from hospital information systems at the participating centers.

#### **Measurements**

Linked patient and family member questionnaires examining smoking status, feelings of guilt and censure, and smoking concealment were developed based on the previous studies [5,17,21]. Both patients and family members were asked to report their smoking status with the question: 'Which of the following best describes your smoking status?' Response options included 'never smoked', 'smoked but quit before (the patient's) cancer diagnosis', 'smoked but quit soon after (the patient's) cancer diagnosis (<1 month; i.e., immediate quitter)', 'continued to smoke after (the patient's) cancer diagnosis (>1 month), but currently not smoking', and 'currently smoking'.

Patients and family members who were currently smoking or who had continued smoking for at least 1 month after the diagnosis (continuing smoker) were subsequently asked questions regarding feelings of guilt and censure, as well as smoking concealment. Guilt was assessed by the question: 'Have you ever felt guilt toward your family members (for the patient)/the patient (for family members) for smoking after (the patient's) cancer diagnosis?' Censure was assessed by asking: 'Have you been criticized for smoking by your family members (for patient)/the patient (for family members) since the patient's cancer diagnosis?' Smoking concealment from the family was evaluated by asking: 'Have you ever kept your smoking status hidden from your family members (for the patients)/the patient (for the family members) since the patient's cancer diagnosis?' Smoking concealment from HCPs was assessed by asking: 'Have you ever kept your smoking status a secret from HCPs since your/the patient's cancer diagnosis?' [5,21]. Study participants were also asked for sociodemographic and medical information.

### Statistical analyses

The prevalence of each smoking status was assessed, and the characteristics of immediate quitters and continued smokers were compared by *t*-test or chi-square statistics. Numbers and percentages were derived from the responses of patients and family members to the questions examining feelings of guilt, censure, and smoking concealment. The extent of

smoking concealment to families and HCPs was compared with regard to their feelings of guilt or censure, both for patients and family members. Chi-square tests were used to determine the statistical difference.

As an exploratory post-hoc analysis, the responses regarding guilt, censure, and smoking concealment were compared according to the anatomical sites and tobaccorelatedness of the patients' cancer (by American Cancer Society definition) and dyadic smoking status (when both patient and family member smoking vs. when patient is not smoking and family member is smoking) by chisquare or Fisher's exact test, as applicable.

All statistical analyses were conducted by using STATA version 12.0 (STATA Corp., Houston, TX), and P-values < 0.05 were considered statistically significant.

# Results

# Prevalence of smoking status among cancer patients and family members

In total, 990 dyads were included in the analysis. Among 188 patients who smoked at the time of diagnosis, 143 (76.1%) reported quitting immediately following diagnosis, 13 (6.9%) reported that they continued smoking for some time but were currently not smoking, and 32 (17.0%) reported that they were still smoking. Among 173 family members who smoked at the time of diagnosis, 22 (12.7%) reported that they quit immediately after the diagnosis, 3 (1.7%) reported that they continued smoking for some time but were currently not smoking, and 146 (84.4%) were still smoking. Continuing smokers did not differ from immediate quitters in terms of sociodemographic or medical characteristics (Table 1).

# Feelings of guilt, censure, and smoking concealment

Most patients who continued to smoke reported feelings of guilt toward their families (75.6%) and felt criticized by their families for smoking (77.8%); almost half of these patients reported having concealed smoking from their family members (44.4%) or HCPs (46.7%). Most family members who continued to smoke reported experiencing guilt toward the patient (63.6%) and felt criticism from the patient for smoking (68.9%); some of these members reported having concealed their smoking from their family members (28.5%) or HCPs (9.3%). Such responses showed no distinct pattern according to the anatomical sites or tobacco-relatedness of the patients' cancer (Table 2). Family members feeling of guilt, censure, and smoking concealment did not differ by patients' smoking status (data not shown).

Patients who reported feelings of guilt were more likely to conceal their smoking from family members (55.9% vs. 10.0%; P = 0.010) or HCPs (55.9% vs. 20.0%; P = 0.046) than were those who did not feel guilty. Censure was not significantly associated with concealment of smoking from family members or HCPs. Family Members who reported feeling guilty (36.5% vs. 16.3%; P = 0.012) or censured (34.5% vs. 16.7%; P = 0.031) were more likely to conceal smoking from patients than were those without those feelings. However, neither guilt nor censure was significantly associated with concealment of smoking from HCPs (Figure 1).

# Discussion

To our knowledge, this is the first nationwide, multicenter study to investigate the prevalence of continued smoking, feelings of guilt and censure, and smoking concealment within the family context. Our data suggest that many patients and family members continue to smoke following cancer diagnosis, and the majority of these people experience feelings of guilt and censure, which can lead to the concealment of smoking status from families or HCPs.

Although a diagnosis of cancer has been regarded as a 'teachable moment' to change the detrimental behaviors of patients [22] and their family members, [16,19] almost a quarter of our patients and majority of family members reported that they continued smoking for at least 1 month after their diagnosis. While the prevalence of continued smoking in our cancer patient sample (45/990 = 4.5%) is much lower than the reported prevalence in Korea (around 25% in adult population) [23], that of patients' family (151/990 = 15.3%) was not very different from that of the general population considering the older age and female predominance of our family sample. Continued smoking by patients is especially problematic because it is associated with a poor response to cancer treatment, increased risk of recurrence and secondary cancer, and mortality [24], and continued smoking by family members is also problematic because it increases the risk of exposure to secondhand smoke, access to cigarettes, and the difficulty of cessation for patients [10]. Although smoking cessation programs, including effective pharmacotherapy, are becoming standard components of survivorship care in some countries like the Netherland [25], active screening and intervention for the survivors and family members are not the norm and are rare in Korea [26].

Of note, the majority of the patients and family members who continued to smoke after a diagnosis of cancer reported that they felt guilty about smoking. Stigma associated with disease depends on whether the patient is held responsible for the disease. And patients who have smoked are at risk of experiencing greater stigma, [15] which may lead to self-blame and guilt [11,27]. Studies showed that family members often promise to quit to support the patient or in response to the pleas of the patient or other family members [9]. However, they may find it difficult to actually quit, and may feel guilty about smoking.

	Cancer	patients		Family r		
	Immediate quitter (N=143)	Continued smoker (N=45)	P-value	Immediate quitter (N=22)	Continued smoker (N=151)	P-value
Age, Mean (SD)	60.3 (12.9)	61.9 (12.1)	0.472	50.7 (14.0)	47.2 (12.8)	0.244
Sex						
Male	3  (77.5)	38 (22.5)		19 (12.2)	137 (87.8)	
Female	12 (63.2)	7 (36.8)	0.164	3 (17.6)	14 (82.6)	0.521
Education						
Less than high school	67 (75.2)	22(24.7)		3 (12.0)	22 (88.0)	
High school and above	74 (77.1)	22 (22.9)	0.774	18 (12.9)	27 (87.1)	0.898
Monthly income						
<2 million KRW	106 (79.7)	27 (20.3)		7 (11.3)	55 (88.7)	
>2 million KRW	36 (67.9)	17 (32.1)	0.088	15 (13.5)	96 (86.5)	0.674
Marital status						
Married	123 (77.4)	36 (22.6)		18 (13.4)	116 (86.6)	
Unmarried	20 (69.0)	9 (31.0)	0.950	4 (10.3)	35 (89.7)	0.600
Patients' cancer type						
Stomach	21 (80.8)	5 (19.2)		l (5.3)	18 (84.7)	
Lung	28 (82.4)	6 (17.6)		2 (15.4)	(84.6)	
Liver	14 (82.4)	3 (17.6)		(  . )	8 (88.9)	
Colorectal	18 (62.1)	11 (37.9)		2 (9.1)	20 (90.9)	
Breast	5 (62.5)	3 (37.5)		7 (10.8)	58 (89.2)	
Cervical	I (50.0)	I (50.0)		(7.7)	12 (92.3)	
Others	56 (77.8)	16 (22.2)	0.353	8 (25.0)	24 (75.0)	0.478
Patients' stage at diagnosis						
In situ and local	38 (66.7)	19 (33.3)		( 8.6)	48 (81.4)	
Regional	48 (82.8)	10 (17.2)		4 (5.5)	69 (94.5)	
Distant	52 (81.3)	12 (18.8)		6 (16.7)	30 (83.3)	
Unknown/missing	5 (55.6)	4 (44.4)	0.075	1 (20.0)	4 (80.0)	0.052
Years since diagnosis, Mean (SD)	1.6 (2.1)	1.8 (2.3)	0.736	1.6 (2.0)	1.4 (1.9)	0.680
Relationship to patient				. ,		
Non-spouse				5 (6.6)	70 (93.3)	
Spouse				16 (16.5)	81 (83.5)	0.05 I

Table I. Characteristics of immediate quitters and continued smokers among Korean cancer patients and family members

Immediate quitter: smoked, but quit immediately after cancer diagnosis (<1 month).

Continued smoker: current smoker and those who continued smoking for at least 1 month after cancer diagnosis.

KRW: Korean Won (2m KRW = \$1800 as of 2012).

P-value: by t-test (continuous variables), chi-square test, or Fisher's exact test (categorical variables) as appropriate.

Table 2. Fe	eelings of guilt and	l censure and	smoking co	ncealment	among ł	Korean	cancer	patients	and far	nily m	nembers	who	continued	to
smoke after	cancer diagnosis													

		Anatomical sites								Tobacco-relatedness			
	All	Stomach	Lung	Liver	Colorectal	Breast	Cervical	Others	P-value	Yes	No	P-value	
Patients (N = 45)		(N = 5)	(N = 6)	(N = 3)	(N =    )	(N = 3)	(N = I)	(N = 16)		(N = 16)	(N=29)		
Felt guilt about smoking	77.3	80.0	83.3	66.7	72.7	66.7	NA	81.3	0.97	86.7	72.4	0.25	
Censured	79.6	60.0	100.0	33.3	72.7	66.7	NA	93.8	0.06	80.0	79.3	1.00	
Concealed smoking from the family	45.5	20.0	50.0	33.3	45.5	66.7	NA	50.0	0.86	60.0	37.9	0.16	
Concealed smoking from HCPs	47.7	60.0	50.0	66.7	36.4	66.7	NA	43.8	0.86	60.0	41.4	0.24	
Family Members (N = 151)		(N = 18)	(N =    )	(N=8)	(N = 20)	(N = 58)	(N =  2)	(N=24)		(N=85)	(N = 66)		
Felt guilt about smoking	66.2	75.0	72.7	87.5	68.4	66.7	33.3	63.6	0.27	64.6	68.3	0.65	
Censured	71.2	68.8	54.6	100.0	63.2	79.3	50.0	68.2	0.11	78.3	61.9	0.03	
Concealed smoking from the patient	29.5	25.0	36.4	87.5	36.8	25.9	8.3	22.7	0.01	31.3	27.0	0.57	
Concealed smoking from HCPs	9.6	12.5	18.2	12.5	0.0	8.6	8.3	13.6	0.55	10.8	7.9	0.56	

Approximately 75% of our patient sample reported having been censured for smoking by their family members. Family members may view the patient as having a self-inflicted disease, consider continued smoking following a cancer diagnosis to be irresponsible, and blame the patient for such behavior [28]. Conversely, family members who continued smoking also experienced censure from their patients. Patients may experience intense worry



Figure 1. Concealment of smoking according to feelings of guilt and censure among Korean cancer patients and family members HCP: Healthcare professional

and concern about the future health of loved ones, and some of them risk sacrificing harmonious relationships by repeatedly confronting family members about continued smoking in an attempt to encourage them to stop [10]. But, such attempts are generally not successful and often result in additional conflict and strained family relationships [10,28]. Therefore, HCPs may need to assess whether patients and family members are censuring the other, educate them of the addictive nature of cigarettes, provide systematic cessation programs (including pharmacotherapy), and help them establish new patterns of interaction that do not involve smoking [10].

These feelings of guilt and of censure can have deleterious consequences, which is concealment of smoking. Studies showed that stigmatized patients and family members may experience poor psychological adjustment, leading to depression and a failure to seek help [17,27,29]. Our study also showed that nearly half of the patients had concealed their smoking from family members or HCPs, respectively, and to a lesser extent, family members also concealed their smoking from patients or HCPs. This is particularly problematic because patients and family members may be important sources of emotional and practical support for their cessation efforts to each other [30], and HCPs are in the best position to help them guit effectively, especially with pharmaceutical methods [5]. The percentage of patients who had ever concealed smoking from HCPs was much higher than

reported for the general population (5.8% in the US general population [31] and 8% in New York City residents [5]). This suggests that cancer patients may experience greater smoking-related stigma than do smokers without a cancer history [5,21], and necessitate more sophisticated communication skills to detect patient smoking. For example, non-judgmental and encouraging questions such as 'Some of my patients have continued to smoke after they were diagnosed with cancer. It can be difficult to quit. How are you doing with this?' rather than 'Do you smoke?' may lead to disclosure of smoking status and open the door for subsequent intervention [5].

One interesting finding is that the feelings of guilt, censure, and concealment of smoking were prevalent regardless of the anatomical sites and tobacco-relatedness of the cancer types. This was unexpected. However, studies showed that at least some patients may believe that their cancer is a result of smoking, although there is no validated causal link between smoking and the cancer they had [27,32]. Therefore, it is likely that many patients in our study attributed smoking as their reason for getting their cancer, and may feel guilty about smoking, regardless of its actual tobacco-relatedness. Similarly, family members may also have similar perception, and may criticize the patients for their continued smoking, even though there is no direct causal link. So, HCPs should not assume that the feelings of guilt, censure, and concealment of smoking are unique problems with lung cancer or other tobacco-related cancers. In addition, the family members' feelings of guilt, censure, and concealment of smoking were not different by patient's smoking status, suggesting that such feeling and behavior is not reduced even though the patient him/herself is smoking.

There are several limitations to this study that should be noted. First, because of social desirability bias, the true rate of smoking concealment was likely underestimated in our study given that we relied on self-reporting [5,21]. However, biochemical measures to validate smoking status are challenging to execute in a large survey study. Thus, our estimates of concealment are likely conservative, and problems associated with feelings of guilt, censure, and smoking concealment could be greater than our analysis suggests. Second, our sample may not be the representative of all cancer patients and family members, given that only patients accompanied by family members were included in the study. This may have introduced bias in the prevalence of continued smoking, feelings of guilt and censure, and smoking concealment. Another limitation of this exploratory study is the small sample size. Although this study was conducted in multiple centers at a national level, the small number of patients and family members who continued smoking after diagnosis reduced our statistical power.

Despite the aforementioned limitations, our study has important implications. Feelings of guilt, censure, and

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concealment of smoking pertinent to cancer survivorship should be considered in the development and implementation of smoking cessation programs for cancer patients and family members. Further studies are warranted to develop systematic approaches to minimize the negative effects from such feelings and behaviors and to enhance mutual support for smoking cessation in the family context [14,17].

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#### **Conflict of interest**

The authors have declared that there is no conflict of interest.

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