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Patient views on smoking, lung cancer, and stigma: A focus group perspective



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A B S T R A C T

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Purpose: Patients with lung cancer, the leading cause of cancer death, are shown to have high levels of psychological distress and poorer quality of life as compared to patients with other cancer types. The purpose of this paper is to describe patient focus group discussions about the lung cancer experience in relation to perceived stigmatization, smoking behaviors, and illness causes; and to discuss implications of these findings relative to the role of the nurse as a patient advocate.

Methods and sample: Eleven adult lung cancer patients participated in audio taped focus group sessions. Discussion questions probed patient perceptions of lung cancer challenges and adaptation issues.

Results: Six primary themes from the qualitative analysis included: 1) societal attitudes; 2) institutional practices and experiences; 3) negative thoughts and emotions such as guilt, self-blame and self-deprecation, regret, and anger; 4) actual stigmatization experiences; 5) smoking cessation: personal choices versus addiction; and 6) causal attributions.

Conclusions: Patients with lung cancer uniquely experience an added burden from developing an illness that the public recognizes is directly associated with smoking behaviors. Stigmatization and smoking related concerns are of high importance. Oncology nurses must be at the forefront in ensuring that patients with lung cancer do not experience additional burden from perceptions that they somehow deserve and need to defend why they have the illness that they are facing.

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Lung cancer is the leading cause of cancer death globally (Lee et al., 2011) and the second leading cancer in incidence in the United States (Siegel et al., 2013). Patients with lung cancer are documented to have high levels of psychological distress, high symptom burden, and poorer quality of life as compared to patients with other cancer types (Hill et al., 2003; Sarna et al., 2004; Schag et al., 1994; Sikorskii et al., 2007; Zabora et al., 2001). Further, because of the linkages of the disease to smoking related behaviors, patients with lung cancer may feel stigmatized following diagnosis (Cataldo et al., 2012; Chapple et al., 2004). Recognizing and understanding patients' perceptions about the lung cancer context and how stigma can potentially impact psychological adaptation to the illness is essential to optimize patient care. The purpose of this paper is to describe patient focus group discussions about the lung cancer experience in relation to perceived stigmatization, smoking behaviors, and illness causes; and to discuss implications of these findings relative to the role of the nurse as a patient advocate.

Background

In foundational early work, the sociologist Goffman defined stigma as "an attribute that links a person to an undesirable stereotype, leading other people to reduce the bearer from a whole and usual person to a tainted, discounted one" (Goffman, 1963, p. 11). Stigma broadly encompasses societal attitudes towards the affected groups, institutional stigmatizing practices, actual discrimination experiences, perceived stigma, and self referenced stigma (Van Brakel, 2006). The societal labeling that characterizes stigma confines the affected person into the role that they are cast, which can lead the person to accept and identify with the prescribed role, a process that can inflict psychological damage (Gonzalez and Jacobsen, 2012).

Recognition of the negative health effects of second hand smoke, and perceptions that smoking is an individualized health choice has increased public stigmatization of smokers (Stuber et al., 2008). Public health campaigns aimed at tobacco control and the generation of smoke free environments, while decreasing smoking rates, have reduced social acceptance of smoking (Cataldo et al., 2012; Chapple et al., 2004; Hammond et al., 2006). Further, socio-

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economic disparities that coincide with reduced access to smoking cessation programs, and tobacco industry campaigns that promote smoking in disadvantaged populations may also increase societal marginalization and the potential for stigmatization of smokers (Stuber et al., 2008). In a large study of smokers ($n = 9058$) that included participants from four major countries, 80% of the sample perceived that society disapproves of smoking, 74% indicated that they intended to quit smoking, and 30% identified that they had made at least one quit attempt (Hammond et al., 2006). Unintended and even unfortunate consequences from health promotion campaigns can be a “blame the victim” mentality that can potentially lead to increased isolation, psychological distress, and diminished quality of life for patients who are facing cancer diagnoses that are attributable to personal behaviors (Else-Quest et al., 2009; Lebel and Devins, 2008; Stuber et al., 2008).

There has been increasing attention to the experience of stigma in patients with lung cancer (Cataldo et al., 2012; Cataldo et al., 2011; Chambers et al., 2012). LoConte et al. (2008) found that patients with lung cancer had higher levels of perceived cancer-related stigma as compared with patients with breast and prostate cancer. In other research, perceived stigma in lung cancer contributed to higher depressive symptomatology above and beyond important demographic, clinical, and psychosocial factors (Gonzalez and Jacobsen, 2012). Smoking and perceptions that the lung cancer was self-inflicted were also associated with higher levels of depression, guilt, shame, and anxiety for affected patients (LoConte et al., 2008). Primary caregivers of lung cancer patients who blame the patient for their illness may be angry and less empathic, with consequences that they may subsequently provide less optimal care (Lobchuk et al., 2008).

In qualitative research conducted in the United Kingdom, Chapple et al. (2004) identified that patients with lung cancer perceived stigma from friends, family, and health professionals because of the disease link to smoking. Perceptions of blame were even experienced by patients who had quit smoking long before the diagnosis (Chapple et al., 2004). Some of these patients did not want to disclose that they had lung cancer due to the fear of stigmatization (Chapple et al., 2004). Further, patients were concerned that access to quality medical care including disregard of symptoms and diagnosis delays was associated with smoker stigmatization (Chapple et al., 2004). In addition, some patients believed that links to smoking were associated with lowered government provision of research funding (Chapple et al., 2004). Patients attributed public negativity to lung cancer as associated with national media campaigns that blame the smoker for acquiring the condition (Chapple et al., 2004). Importantly, many of the patients who attended support groups resisted self-blame and identified potential causes for the lung cancer other than cigarette smoking (Chapple et al., 2004).

While the role of smoking in the evolution of the illness is non-disputed, about 25% of lung cancers occur in nonsmokers (Lee et al., 2011). Further, lung cancer presents only in a subsample of heavy long-term smokers and occurs in family aggregates (Yang, 2011). More recently, an increasing literature has targeted the role that genetics play in the development and progression of lung cancer (Lee et al., 2011; Yang, 2011). For example, candidate gene studies have identified two distinct genetic polymorphisms that specifically affect lung cancer patients with no smoking history (Yang, 2011).

Lung cancer represents a heterogeneous group of malignancy types, with variation in terms of patients affected. As a case in point, bronchioalveolar adenocarcinoma is shown to be more common in non-smokers, women, and Asians (Yang, 2011). New targeted therapies such as the epidermal growth factor receptor-tyrosine kinase (EGFR-TK) inhibitors demonstrate significant therapeutic

efficacy for selected patients, with activated EGFR mutations occurring more frequently in individuals without smoking history (Lee et al., 2011). Importantly, lung cancer risk is also heightened by exposures to radon, indoor pollution from burning coal and cooking oil, and asbestos (Yang, 2011). More recently, the World Health Organization listed air pollution as an important causal factor for lung cancer (International Agency for Research on Cancer, 2013). There is increased recognition that complexities in the evolution of lung cancer and its treatment make the focus on smoking less important to individual presentations (Lee et al., 2011).

Smoking is publicly considered a controllable behavior in the evolution of health problems such as lung cancer (Stuber et al., 2008). Thus it seems important to understand how this commonly recognized association affects the lived experience of patients who have been diagnosed and treated for lung cancer. The context of a focus group permits patients with homogenous backgrounds to share their perspectives in a format where they can exchange meaningful information amongst themselves (Krueger and Casey, 2000). Focus groups may reduce power differentials between researchers and participants by capitalizing on the group peer dynamic which can also foster uninhibited discourse (Barbour, 2005). Thus, the focus group setting provided a unique opportunity to better understand the role of smoking, stigma, and the experience of lung cancer for patients. The study purpose is to describe patient focus group discussions about the lung cancer experience in relation to perceived stigmatization, smoking behaviors, and illness causes; and to discuss implications of these findings relative to the role of the nurse as a patient advocate. The study extends the findings from Chapple et al. (2004) earlier qualitative study conducted with patients from the United Kingdom to include patients with lung cancer from the Midwestern region of the United States.

Methods

The findings are derived from a focus group study that aimed to elicit lung cancer patients perceptions about using mindfulness-based strategies to manage symptoms during treatment (Lehto and Wyatt, 2013). During discussion of major challenges experienced during lung cancer adaptation, the experience of stigma, smoking behaviors, and disease causes were a major topic of spontaneous discourse and thus are the focus of this paper. The University and community site Institutional Review Boards approved the study, and all participants provided signed informed consent. Participants were eligible if they were: 1) ≥ 21 years of age; 2) able to travel to the focus group site and participate in a 2-h group session; 3) completed treatment for non-small cell lung cancer; and 4) were at least six months post diagnosis.

Study participants were contacted by telephone from a confidential list of patients who were treated for non-small cell lung cancer at the participating community hospital site located in the Midwestern part of the United States, which drew patients from a community based primarily rural area. The purpose of the focus groups, the voluntary nature, the use of audio recording, and location, date, and time were discussed during the telephone contact.

The four group groups were composed of a total of 11 Caucasian older adults (mean age 69.8 ± 8.5 , range 51–79 years) with a history of non-small cell lung cancer. The majority of the sample was married ($n = 6$, 55%) and female ($n = 6$, 55%), and most had at least a high school education (mean 12.3 ± 2 , range 9–16 years). Most participants were either retired or on disability ($n = 10$, 91%), and all were functionally independent. The first focus group ended up being an in-depth interview due to only one participant in attendance. The other three groups were comprised of 3, 3, and 4 participants for a total of 11 participants. Six people did not attend

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