SHAME AND GUILT IN LUNG CANCER
The stigma of lung cancer

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ABSTRACT
Lung cancer patients report higher levels of distress than patients in all other cancer groups. The stigma of lung cancer’s association with smoking, recognized by the public and healthcare professionals alike, contributes to patients’ feelings of shame and guilt, and in turn, their illness burden. Only a limited number of studies examine shame and guilt in lung cancer patients. This article summarizes literature investigating whether patients’ shame, guilt and experience of social stigma perpetuate their distress. Research could make possible a deeper understanding of the effects of shame and guilt in the journey for lung cancer patients, as well as lead to effective interventions.

INTRODUCTION
Lung cancer patients report the highest burden of distress of all cancer groups.1-7 Despite evidence that interventions may improve quality, and possibly quantity of life,8-11 they access healthcare professionals for help less often than other cancer groups.12-14 experiencing distress at diagnosis may be normal since lung cancer patients have a poor prognosis,7 and receive their diagnosis at an advanced stage.15 However, newly diagnosed patients report more psychosocial than physical concerns, and these concerns remain throughout their cancer journey.16 This pattern of distress combined with lack of help-seeking has led researchers to look for explanations and seek ways to improve quality of life.

Due to the link between smoking and a later lung cancer diagnosis, current and former smokers may feel responsible for their cancer17 and hide from others due to their shame and guilt.18,22,24 Feelings of shame and guilt can affect medical treatment by delaying symptom reporting,15,23 increasing false reporting or non-disclosure to doctors about smoking habits,25 and in addition to poor prognosis and advanced state of disease, may in part account for a lack of success.
in creating lung-cancer support groups/advocacy.19 Feelings of shame and guilt can cause emotional suffering that may increase the illness burden, lead to social isolation, and contribute to ongoing distress. Social isolation not only affects their quality but also quantity of life.26

STIGMA
Smokers and nonsmokers alike experience and fear the stigma associated with lung cancer.18,21 A large population-based survey examined respondents’ willingness to attribute blame across cancer groups. Although their sample consisted of women, who generally hold positive attitudes towards individuals in need of support,27 70% attributed blame to lung cancer patients, as opposed to 9% blame attribution for leukemia and 15% for breast cancer.26 The blame attributions for lung cancer were similar to conditions more widely seen as a matter of individual responsibility, such as chlamydia and obesity.28

Healthcare professionals and the lay public recognize the stigma lung cancer patients experience. In an interview study, 18 oncology social workers reported that stigma related to cigarette smoking was a principal reason for patients’ emotional burden.19 Six focus groups made up of healthcare professionals and members of the public identified shame and blame as a main impediment to lung cancer patients’ coping.23 This stigma is also present in the news. In a study of all cancer-related stories presented on Australian television news, only 2% related to lung cancer although it is the leading cause of cancer death. Furthermore, 62% of these reports addressed lung cancer in nonsmokers.29 Both this underrepresentation of the disease and the portrayal of mainly nonsmokers as deserving of sympathy may perpetuate the stigma and shame among patients with lung cancer, especially in those who have smoked. Anti-smoking campaigns, which are important in order to prevent young people from starting smoking and encourage smokers to quit, can also have an unintended consequence of upsetting those with smoking-related illness and perpetuating stigmatization.28

FUTURE DIRECTIONS
The majority of studies on shame and guilt in lung cancer have used qualitative methodology and have highlighted the prevalence and debilitating consequences. These studies are a starting point for future research to understand how these emotions affect patients and to test ways to combat these emotions so patient care can be improved.24 Past research has uncovered several areas that need attention. Teaching lung cancer healthcare teams to recognize the signs of shame and guilt in their patients may empower them to reach out more empathically to their patients and refer them more often for psychosocial care. Healthcare professionals play a large role in alleviating distress by being aware of the high psychosocial needs of this population,13,16 There is room for improvement when it comes to physician-patient communication. In a study of oncologists’ and surgeons’ responses to lung cancer patients’ concerns in consultations, they responded empathically to only 10% of patients’ concerns, emotions or mention of a stressor.30 Empathy in physician-patient communication has been associated with patient satisfaction and improved adherence to treatment,31 and need not delay consultations.27

There is also a need for research to evaluate interventions that target shame and guilt and interrupt the cycle of distress. A more sensitive approach to anti-smoking campaigns18,20,28 using nonjudgmental and nonblaming material20 that acknowledges how hard it is to change health behaviour might reduce the stigma.28 Not so long ago, smoking was pervasive, acceptable and encouraged by tobacco advertising. Education about this might

Approach to addressing shame and guilt in lung cancer patients

- Recognize the signs of shame and guilt (e.g. social withdrawal/isolation; physical and verbal cues including a head-down, gaze-down position often occurring with pauses or breaks in speech)
- Inquire about emotional state16
- Administer a form of distress screening12
- Refer to counselling services19
alter the judgmental attitude experienced by lung cancer patients who smoked. If reducing the shame experienced by patients can decrease the delay in reporting symptoms, diagnosis and access to more treatment options may occur earlier.

In summary, this developing literature offers important clues to the cycle of distress lung cancer patients experience. Cancer patients at any stage are susceptible to guilt and shame and research should examine if there is a different effect based on disease stage. More research is crucial to understand these patterns, intervene more effectively and improve quality of life for lung cancer patients.

REFERENCES


Disclosure

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