Lung Cancer Stigma across the Social Network: Patient and Caregiver Perspectives

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ABSTRACT

Objective: To examine the personal experiences of people with lung cancer and their caregivers and how stigma is manifested throughout a patient's social network.

Methods: A qualitative thematic analysis of interviews with 28 patients with lung cancer and their caregivers was conducted. Telephone interviews were conducted and transcribed verbatim. Data analysis was guided by contemporary stigma theory.

Results: Patients and caregivers reported feeling high levels of felt stigma and concomitant psychological distress in response to the diagnosis of lung cancer. Three overarching themes emerged: the nexus of lung cancer and smoking, moralization, and attacking the link between lung cancer and smoking. Stigma was inevitably linked to smoking, and this formed the hub around which the other themes were organized. Caregivers reported feeling invisible and noted a lack of support systems for families and caregivers. In addition, there was evidence that caregivers experienced stigma by association as members of the patients' close networks. Both groups responded ambivalently to stigmatizing antismoking advertisements.

Conclusions: The qualitative analysis demonstrated the complex interplay of the social and personal domains in the experience and outcomes of stigma in lung cancer. There is a significant potential for caregivers of patients with lung cancer to experience exacerbations of psychosocial distress as a consequence of widely shared negative views about lung cancer and its prognosis. It remains for researchers and practitioners to incorporate such complexity in addressing stigma and psychosocial distress in both patients and caregivers.

Introduction

In Australia lung cancer is the fifth most commonly diagnosed cancer, with an estimated 12,434 new cases in 2017,[1] and the prevalence projected to rise in the future.[2] Although age-standardized incidence and mortality rates have decreased steadily for men, they have increased for women, who will represent 40% of new cases in 2017.[1] The increase of lung cancer in women has seen it overtake breast cancer as the most significant cancer, yet the advocacy and support for lung cancer has yet to catch up. Contrary to the improved survival outcomes for many cancers, the prognosis for people in whom lung cancer has been diagnosed remains poor, with 5-year relative survival rates of 14% for men and 19% for women for the period 2009–2013.[1] The most common cause of lung cancer is smoking, with occupational carcinogens also implicated.[3] People with lung cancer report higher levels of psychological distress, greater unmet needs, and a greater risk of suicide than do other patient groups. Up to 62% of patients with lung cancer report significant psychological distress[4]; for many, this distress does not ameliorate over time, and indeed, it may worsen.[5] Patients with lung cancer have a rate of suicide (81.7 per 100,000 person-years) that is up to eight times higher than the rates of those with other cancers such as breast, prostate, and colorectal cancer and almost five times the rate of the general population.[6] Adding to this picture, patients with lung cancer, more so than patients with other cancers, feel stigmatized owing to their disease, and this feeling of stigmatization increases their psychological distress.[7]

Stigma may be an unintended outcome of public health programs concentrating on reducing rates of smoking to combat the incidence of lung cancer. Mass media advertising emphasizes smoking's health risks, including the risk of lung cancer. The ensuing stigmatization of smokers is regarded as a motivator for behavior change.[8–10] In Australia, federal and state governments have mandated increasing levels of graphic and potentially stigmatizing health warnings on cigarette packets, culminating in 2012 with plain packaging of cigarettes and a large proportion of the packet covered by a graphic image, such as that of a diseased lung. Smoke-free workplace laws have further marginalized smokers. Thus, researchers argue that an ethical burden exists to address the disproportionate experience of stigma among patients with lung cancer that is associated with negative sequelae, such as treatment deferral and increased distress.[11,12] A deeper examination of the stigma construct is required to understand the complex associations between the stigma of lung cancer and psychosocial outcomes.

In recent years, since Erving Goffman's[13] preeminent contributions, the concept of stigma has undergone considerable theoretical refinement[14] from both sociological perspectives,[15] emphasizing a stigmatized identity within a given social context and sociopsychological contexts,[16,17] focusing on individual responses to stigmatized identities. Contemporary accounts of stigmatizing processes emphasize group identities and are based in the differential power relations accompanying stigma. From a contemporary perspective, stigma can accrue both to the person who is a member of a marked category (e.g., a patient with lung cancer) and to that person's immediate familial networks (i.e., stigma by association[18]). Stigma may be manifest in several experiential forms that are often grouped under the term *enacted* or felt stigma.[14,19] Patients with lung cancer and their caregivers may perceive being devalued by others, may anticipate negative affect and discriminatory behavior, and may even endorse (or internalize) such stigma themselves. Not surprisingly, such stigma is associated with treatment delay and other maladaptive outcomes.[7,20]

Although previous studies of stigma in lung cancer have provided valuable insights into experiences at the level of the individual patient,[21] examinations of the stigma of lung cancer have yet to incorporate a genuinely multilevel perspective that considers multiple facets of the patient's familial and social networks. Researchers have increasingly recognized the important role that close family members (often, significant others) play in providing tangible and emotional support and in their connections with patients across the cancer journey, which although not clearly defined, is often termed *informal caregiving.*[22] This work also highlights the high emotional and financial costs and notes the particular challenges of caregiving in lung cancer. Caregivers are recognized to be a vulnerable population that in providing crucial psychosocial support, are at risk of increased psychological distress and other unmet needs.[23]

These phenomena require rigorous examination. However, existing quantitative measures of stigma may not be sufficiently sensitive for this purpose. Instead, qualitative analysis of fewer participants in great depth may allow stronger, more stable conclusions. Qualitative analysis gains rigor when it is performed, as in the present case, under the guidance of well-defined theory associated with a coherent body of empirical results. A recent review[7] found that qualitative studies of lung cancer stigma had suffered from a lack of a clear theoretical model of stigma. To enhance rigor and stability, researchers first identify theoretically consistent patterns or themes that appear consistently across participants and then collect illustrative individual utterances, often comparing and adjusting classification iteratively.