A Pilot Mixed-Methods Study of Malignant Pleural Mesothelioma Symptoms

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OBJECTIVES: To describe symptoms of malignant pleural mesothelioma (MPM), a rare cancer associated with a poor prognosis and significant symptoms, via a pilot mixed-methods study, because it is unclear whether MPM symptom assessment tools accurately characterize these symptoms.

SAMPLE & SETTING: Participants with MPM were recruited from a large northeastern U.S. academic medical center with an interprofessional MPM program.

METHODS & VARIABLES: A mixed-methods pilot approach was employed using the Lung Cancer Symptom Scale for Mesothelioma (LCSS-Meso) to quantitatively describe MPM symptoms and semistructured interviews to qualitatively capture these symptoms.

RESULTS: Seven participants with MPM completed the LCSS-Meso and qualitative interviews. The five symptoms evaluated by the LCSS-Meso were confirmed as symptoms of MPM in participant interviews. However, the presence and severity of some symptoms were either under- or overestimated by the scale. Two additional symptoms, distress and sleep disturbance, also emerged from the qualitative interviews.

IMPLICATIONS FOR NURSING: Nurses caring for people with MPM should have a thorough understanding of common symptoms, but they must also explore additional symptoms that are meaningful to each patient.

Malignant pleural mesothelioma (MPM) is a rare but deadly cancer that arises in the pleural lining of the lung, is highly associated with asbestos exposure, and can have a lengthy latency period of approximately 40 years (Reid et al., 2014). People with MPM have a poor prognosis, with five-year survival rates of only 10.7% and median survival rates of fewer than six months if left untreated (Howlader et al., 2020; Saddoughi et al., 2018). In addition to poor survival, people with MPM have significant symptoms such as pain, dyspnea, fatigue, loss of appetite, and cough (Hollen et al., 2004; Mendoza et al., 2019).

Several quantitative tools have been adapted to measure MPM symptoms (see Figure 1). These tools are the Lung Cancer Symptom Scale for Mesothelioma (LCSS-Meso) (Hollen et al., 2004), the European Organisation for Research and Treatment of Cancer (EORTC) Quality-of-Life Questionnaire–Core 30 (QLQ-C30) (Aaronson et al., 1993), the EORTC Quality-of-Life Questionnaire for Lung Cancer (QLQ-LC13) (Nowak et al., 2004), and the MD Anderson Symptom Inventory Malignant Pleural Mesothelioma Module (MDASI-MPM) (Cleeland et al., 2000; Mendoza et al., 2019; Williams et al., 2018). The LCSS-Meso, which was modified from the Lung Cancer Symptom Scale (Hollen et al., 1993), measures general MPM symptoms as well as symptom distress, interference with activity level, and global quality of life (Hollen et al., 2004, 2006). The EORTC QLQ-LC13 is a lung cancer–specific supplement to the EORTC QLQ-C30, a general cancer symptom scale measuring various disease-related and treatment-induced symptoms, as well as global health and quality of life (Aaronson et al., 1993). The QLQ-LC13 assesses lung cancer symptoms as well as treatment-related side effects (Bergman et al., 1994). The MDASI-MPM is based on the MD Anderson Symptom Inventory cancer symptom measurement tool, and it is the only