

# Pleural mesothelioma: management updates and nursing initiatives to improve patient care

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**Abstract:** Malignant pleural mesothelioma is a relatively rare but aggressive malignancy that is primarily associated with occupational asbestos exposure. While treatment options for mesothelioma have expanded, the disease carries a poor prognosis, with a median of 8 months to 1 year of survival postdiagnosis. This article synthesizes current disease-management practices, including the diagnostic workup, treatment modalities, emerging therapies, and symptom management, and identifies comprehensive nursing strategies that result in the best care based on updated evidence. Multidisciplinary coordination, palliative care initiation, survivorship, and end-of-life care are discussed. Findings may be applied in clinical environments as a resource to help nurses better understand treatment options and care for patients facing malignant pleural mesothelioma. Recommendations for future research are made to move nursing science forward and to improve patient well-being and health-related quality-of-life outcomes for patients and their family members.

**Keywords:** pleural mesothelioma, cancer, symptom management, evidence-based care

## Introduction

Malignant pleural mesothelioma is a relatively rare but aggressive malignancy that is primarily associated with asbestos-fiber exposure.<sup>1</sup> While treatment options for mesothelioma have expanded, the disease carries a poor prognosis, with a median of 8 months to 1 year of survival postdiagnosis.<sup>2</sup> While there is no cure for pleural mesothelioma, survival and prognosis varies widely, and 3%–5% of patients may survive beyond 5 years.<sup>2</sup> Compared to other cancers, the patient perspective of the pleural mesothelioma experience is less understood.<sup>3</sup> Importantly, despite mesothelioma's relatively low incidence, the disease is increasing in occurrence worldwide, treatment options are evolving, and nurses must be aware of current practice standards to ensure that patients receive optimal care.<sup>4</sup> The purpose of this article is to review current disease-management practices and symptom management, and to identify nursing initiatives that result in the best care based on updated evidence. Discussion will include the essential domains of care through the survivorship spectrum.

## Methods

The CINAHL (Cumulative Index to Nursing and Allied Health Literature), Evidence-Based Medicine Reviews, Health and Wellness Resource Center, PsycInfo, and PubMed databases were systematically reviewed for the years 2006 to 2014. Inclusion criteria were 1) focus on malignant pleural mesothelioma, 2) symptom management for mesothelioma, 3) mesothelioma-treatment strategies, and nursing care

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for mesothelioma. Exclusion criteria included articles that focused on other pulmonary conditions, such as lung cancer and nonpulmonary mesothelioma. The article reports on historical background, diagnostic workup, treatment modalities, symptom management, and nursing initiatives relative to survivorship, palliative care, and end of life.

## Historical background

Mesothelioma is a rare form of cancer that affects the mesothelial cells that coat major body organs. The three major types of mesothelioma are 1) pleural, which is by far the most prevalent and affects the parietal and visceral pleura that line the lung; 2) peritoneal, which affects the peritoneum lining the abdominal cavity; and 3) pericardial, which occurs in the lining of the heart.<sup>5</sup> Malignant pleural mesothelioma is generally localized in the pleural cavity, and spreads directly, causing pressure on vital organs in the thoracic cavity (lungs, heart), which causes pleural effusion, respiratory failure, cardiac tamponade, and even spinal cord compression.<sup>6</sup>

At least 70% of all mesothelioma cases are related to occupational exposure to asbestos fibers.<sup>7</sup> Asbestos is a silicate mineral that was used widely in building-construction materials until nationally enforced environmental regulations became more common.<sup>5</sup> Patients may also be exposed to asbestos by way of proximity to factories where asbestos products are created or used, living in areas of natural asbestos occurrence, private activities, and contact via negligent removal of asbestos from construction sources or old buildings.<sup>8</sup>

In the UK, mesothelioma death rates increased 12-fold between 1968 to 2001.<sup>9</sup> In 1989, the US Environmental Protection Agency issued a ban on the use of asbestos in new products.<sup>10</sup> While Western Europe and the US have enacted such regulatory controls on the use of asbestos, other countries in the developing world often lack oversight on the use, import, and export of asbestos products.<sup>7</sup> It is anticipated that mesothelioma mortality rates will increase 5%–10% per year in industrialized nations until 2020.<sup>11</sup> The development of pleural mesothelioma has a prolonged latency, with disease manifestation occurring 25–71 years following asbestos exposure.<sup>11</sup> Population studies demonstrate that the greatest risk factors for the disease include male sex and older age, because of the history of occupational asbestos exposure.<sup>7</sup> About 80% of all mesothelioma cases occur in men (ratio 5:1) who are over age 50 years.<sup>10,12</sup> In the US, persons who have known occupational exposure to asbestos have been mandated by the federal Occupational Safety and Health Administration to receive ongoing monitoring that includes

chest radiography, comprehensive medical examination, and pulmonary function testing.<sup>13</sup> Mesothelioma-screening programs, including the use of computerized tomography, have not however proven effective in diagnosing early onset of the disease.<sup>13</sup> Mesothelioma development takes decades to develop, and many exposed patients have abnormal lung findings, such as the development of benign pleuritic plaques and pleural thickening that do not lead to mesothelioma occurrence.<sup>14</sup>

## Disease presentation and diagnosis

Although early detection and treatment may result in a better prognosis for mesothelioma,<sup>15</sup> the disease is usually advanced at diagnosis.<sup>16</sup> Most cases of pleural mesothelioma present symptomatically because of dyspnea and/or pain.<sup>7,17–19</sup> Patients may also have malignant pleural effusions with shunt effects and contralateral lung impairment noted on chest X-ray at diagnosis.<sup>20,21</sup> Pulmonary function tests may show a marked ventilatory defect characterized by lowered total lung capacity with a normal ratio of expiratory volume to vital capacity.<sup>22</sup> The symptoms associated with mesothelioma presentation, however, are often nonspecific and similar to other intrathoracic diseases, which can lead to several-month delays in diagnosis.<sup>8,16</sup> Further, there is variation in access to expert mesothelioma care, with institutional reliance on existing care standards in place for lung cancers, which are very different types of cancer.<sup>3</sup> Patients who live in remote geographical areas may have barriers related to access to information and health care, and delays in referral to palliative care services.<sup>23</sup> In addition, the US-based Surveillance, Epidemiology, and End Results (SEER) database also demonstrates that African American race is associated with worse outcomes, due to disease presentation at later stages and lowered access to quality medical care.<sup>24</sup>

The role of biomarkers in the diagnosis of pleural mesothelioma is evolving. Traditional biomarkers have not been effective in discriminating mesothelioma from other cancer types.<sup>25</sup> Diagnostic biomarkers that appear to be most effective at this point include osteopontin, soluble mesothelin, and megakaryocyte-potentiating factor, but these still have specificity and validity concerns.<sup>25</sup> Although non-invasive testing with computerized tomography, magnetic resonance imaging, and ultrasonography can augment the diagnostic workup, the diagnosis of mesothelioma requires a biopsy to obtain tumor cells.<sup>8,26</sup> While there are several staging systems available, the International Mesothelioma Interest Group has developed a TNM (Tumor characteristics, lymph Nodes, Metastasis) staging system that is

approved by the American Joint Committee on Cancer, and is most commonly used to determine the severity of disease.<sup>10,16,20,27</sup> In addition to staging from I to IV, tumor histology (epithelioid, biphasic, sarcomatoid) and performance status are important prognostic factors.<sup>17,28</sup> Of the histologic presentations of the tumor, the epithelioid variant is the most common, and progresses more slowly than the sarcomatoid and biphasic subtypes.<sup>2,28,29</sup> The biphasic subtype has features of both epithelioid and sarcomatoid variants, with an overall prognosis between the two subtypes.<sup>28,29</sup> Patients with sarcomatoid tumors have poor comparative outcomes.<sup>28</sup> In addition to disease staging, patients also undergo assessment of cardiac status, pulmonary function testing, and comorbidities.<sup>16</sup> Mesothelioma patients, who are generally older, may also have comorbid pulmonary conditions, such as chronic obstructive pulmonary disease, diabetes, and congestive heart failure.<sup>30</sup> The European Organization for Research and Treatment of Cancer (EORTC) prognostic index is often used to categorize treatment groups.<sup>31</sup> Reduced functional status and lowered quality of life at diagnosis are associated with lowered survival.<sup>32</sup> Other research has identified performance status, hemoglobin level, and absence of chest pain as important prognostic features.<sup>33</sup>

Following diagnosis of this aggressive life-threatening disease, the information must be sensitively communicated to the patient. Effective communication requires that patients be prepared for the information by having family members or significant others present, tailoring information in a clear, understandable, and honest manner, ensuring privacy and adequate time, offering support, encouraging expression of feelings and concerns, and involving the patient in decision making and the treatment plan.<sup>34</sup>

## Disease management

Traditional options for medical management of pleural mesothelioma may include surgery, chemotherapy, and radiation therapy.<sup>35,36</sup> Types of treatment offered to patients often depend on geographic location, access to cancer centers, availability of multidisciplinary teams, and access to clinical trials.<sup>1</sup> Low incidence of pleural mesothelioma in comparison to other cancers makes clinical trial participation problematic, and thus many clinical trials involving mesothelioma are smaller with single arms.<sup>37</sup> However, there are a multitude of clinical trials available to patients with pleural mesothelioma.<sup>12</sup> Patients are best cared for at tertiary cancer centers able to integrate services from oncologists, surgeons, and radiologists who work together to coordinate and deliver care.<sup>8</sup> Such environments also participate in cancer trials, and

are able to list their patients in cancer registries.<sup>8</sup> Treatment toxicities can be excessive with mesothelioma protocols, making it necessary to make realistic and informed decisions relative to whether to pursue aggressive treatment.<sup>38</sup> Clinical practice guidelines based on systematic evaluation of research findings relative to the best treatment approach are available with recommendations for the multidisciplinary team.<sup>39,40</sup>

## Surgery

According to the US-based SEER database, about 22% of patients with pleural mesothelioma undergo surgery, although rates vary regionally.<sup>24</sup> Patients who receive care in tertiary specialty cancer centers are significantly more likely to have surgery compared to patients in other settings.<sup>24</sup> Evaluation of surgical potential will include disease stage, cardiopulmonary reserve, functional status, surgical expertise and program philosophy, and options for adjuvant treatment.<sup>41</sup> Major goals of surgery are to reduce volume and remove the cancerous area.<sup>42</sup> Of surgical options, extrapleural pneumonectomy, which entails removal of the affected lung, is the most aggressive surgical option and may be considered too extreme for many patients because of the extensiveness of the procedure and the serious peri- and postoperative challenges.<sup>21,43</sup> The second surgical option is pleurectomy/decortication, which encompasses resection of the visceral and parietal pleura without lung resection.<sup>44</sup> Video-assisted thoracic pleurectomy surgery is also an option that permits palliation of symptoms from the tumor.<sup>40</sup> While earlier studies indicated that extrapleural pneumonectomy carried longer median survival, a recent randomized feasibility trial did not find benefits of extrapleural pneumonectomy over trimodal therapy.<sup>45</sup> Further, extrapleural pneumonectomy leads to reduced pulmonary function and increased dyspnea, and has a negative impact on quality of life.<sup>43,44</sup> A review of the literature suggested that extrapleural pneumonectomy showed no survival or symptom-management benefits over supportive care, because of high disease recurrence and operative mortality.<sup>46</sup>

## Radiation therapy

The role of radiation therapy in pleural mesothelioma is primarily palliative.<sup>29</sup> Radiation therapy is not effective as a single treatment for mesothelioma, but plays a role in management of tumor seeding following thoracoscopy, biopsies, and cytoreductive surgery.<sup>29,47</sup> Biopsy procedures used to diagnose mesothelioma may contribute to the development of subcutaneous metastasis, which results in tumor growth along the biopsy scars.<sup>47-49</sup> Therefore, prophylactic radiation to the biopsy site is conducted, but remains controversial in some

environments as a regular practice.<sup>48,49</sup> There are inherent difficulties in the provision of radiation therapy as a treatment strategy in mesothelioma, due to the broad area involved that is closely aligned with radiosensitive critical healthy organs, such as the heart and liver.<sup>47,50</sup> However, radiation therapy is effective in managing chest pain that is nonresponsive to traditional treatment methods.<sup>31</sup> Radiation therapy may also be used prophylactically to decrease the recurrence risk and for disease control following other treatments.<sup>31</sup> Importantly, it has been demonstrated that intermediate doses of radiation therapy produce significant tumor-response rates in patients with strong EORTC prognostic indices.<sup>31</sup>

## Chemotherapy

First-line systemic chemotherapy has evolved from single-agent use of cisplatin to combination treatment with cisplatin and antifolate drugs, which is the current treatment standard and is backed by large randomized clinical trials demonstrating survival benefit, symptom improvement, and enhanced quality of life.<sup>17,51,52</sup> Most patients who receive treatment with first-line chemotherapy will invariably have disease progression, and will later receive second-line combination-agent treatment.<sup>17,53</sup> A review of several Phase II and III clinical trials incorporating multiagent chemotherapeutic agents (cisplatin or carboplatin, mitomycin c, vinblastine, raltitrexed or pemetrexed, gemcitabine, vinorelbine, epirubicin, liposomal doxorubicin) have demonstrated response rates ranging from 16% to 48% and median survival from 7 to 16.8 months.<sup>40</sup>

Patients who are eligible for chemotherapy are those who have Karnofsky functional status scores greater than 60.<sup>8</sup> Patients receiving chemotherapy may experience dose-limiting toxicities and treatment-related symptoms. Toxicities vary in accordance with the type and dosage and combinations of chemotherapeutic agents, and may include hematologic (neutropenia, thrombocytopenia, and anemia) and nonspecific (nephrotoxicity, ototoxicity, nausea, vomiting, diarrhea, anorexia, pulmonary edema, encephalopathy) impact.<sup>54</sup> Palliative chemotherapy may be also offered to support patients with rapidly progressing disease and/or severe symptoms to promote quality of life and ease symptoms.<sup>18,55</sup> However, the use of palliative chemotherapy at the end of life should be carefully considered, with one study demonstrating shorter survival and poorer outcomes for pleural mesothelioma patients treated in their last month of life.<sup>56</sup>

## Multimodality therapies

Multimodality treatment that includes surgery followed by radiation therapy and chemotherapy is increasingly utilized

for mesothelioma patients with early stage disease.<sup>20,42,57</sup> The aim of the multimodal approach is to resect the tumor, and then provide adjuvant therapy to eradicate residual microscopic disease.<sup>58</sup> For example, hemithoracic radiation therapy may be delivered after extrapleural pneumonectomy to reduce the chance of local recurrence, and chemotherapy to offset the possibility of distant metastasis.<sup>59–61</sup> Adjuvant radiation therapy following extrapleural pneumonectomy has resulted in survival gains in recent evaluations.<sup>61</sup> Another form of multimodality treatment is the provision of neoadjuvant chemotherapy prior to surgery. Neoadjuvant systemic chemotherapy is thought potentially to improve chemotherapy-dose tolerance and treatment response.<sup>10</sup> While multimodality therapy may result in longer survival, the treatment is effective for only a subset of patients, and has extensive side effects and cost.<sup>28</sup>

## Current and emerging research trends

Targeted therapies and biological treatments are currently under investigation for mesothelioma.<sup>62,63</sup> This research direction examines molecular pathways that are involved in carcinogenic transformation, including the roles of cellular growth factors, genetic cellular mutations, and signaling pathways involved in cell proliferation and migration.<sup>5,64</sup> The role of immunotherapy, such as the intrapleural administration of interleukin 2, a proinflammatory cytokine, prior to surgery has shown preliminary prognostic impact.<sup>65</sup> Other therapies in Phase I, II, and III trials include bevacizumab, sorafenib, cediranib, bortezomib, dasatinib, belinostat, vorinostat, valproate, cetuximab,<sup>51</sup> and thalidomide.<sup>51,66</sup> Response rates are mixed, with progression-free survival of 1–6.9 months and overall survival of 4.4–15.6 months.<sup>51</sup> Testing for ways of improving outcomes for mesothelioma also includes ongoing research for biomarkers that would aid in early detection, diagnosis, and prognosis.<sup>5</sup>

A clinical trial currently under way aims to combine pleurectomy with intraoperative hyperthermic chemotherapy to determine whether the elevated temperature augments the capacity of the chemotherapy to penetrate tumor cells.<sup>8</sup> Another less common experimental treatment is photodynamic therapy, which uses a porphyrin-based compound that reacts to light to destroy tumor cells.<sup>16,67</sup> There are also current clinical trials investigating the role of gene therapy, which may be available to patients at cancer research referral centers.<sup>68</sup> Gene therapies eradicate tumor cells via genetic modifications, usually accomplished by insertion of a therapeutic gene using vectors, such as adenoviruses.<sup>6,51</sup>

Nurses who care for patients with mesothelioma who are interested in experimental therapies can examine trial websites for specific information about the respective studies.

## Symptom management

Effective symptom management of both psychological and physical illness sequelae can be a critical nursing challenge in the care of mesothelioma patients.<sup>69</sup> Major symptoms experienced by patients include shortness of breath and dyspnea, pain, such psychological symptoms as worry, chest pain, cough, diaphoresis, and constipation.<sup>70</sup> Health-related quality of life, as measured by such baseline symptoms as anorexia, fatigue, and dyspnea, activity interference, and global quality of life, are associated with pleural mesothelioma survival after adjusting for previously mentioned prognostic indicators.<sup>71</sup> Ongoing assessment of symptoms is essential to optimize the health-related quality of life for this population.<sup>71</sup> Symptom assessment that includes subjective data relative to location, pattern, intensity, onset, duration, and alleviating/aggravating factors is essential. Objective assessment data are also necessary for effective management.

## Psychological symptoms

A recent study found that mesothelioma patients did not have their psychological needs sufficiently addressed in the early period following diagnosis.<sup>72</sup> The first 3 months following diagnosis are a particularly stressful period characterized by high uncertainty and perceptions of lack of control.<sup>72</sup> Further, despite the high need for psychological support, there are few support groups available to these patients.<sup>73</sup> Another study found that patients experienced significant traumatic stress symptoms that were associated with depressive symptoms, heightened anxiety, somatic issues, and social dysfunction.<sup>74</sup> Patients may have cognitive complaints, including memory difficulties, problems with focus and concentration, indecisiveness, and difficulties solving problems.<sup>75</sup> Further, patients may also feel anger, betrayal, and ambivalence towards their former employers when they causally attribute the mesothelioma diagnosis to workplace asbestos exposure.<sup>23</sup> Psychiatric consultation and psychopharmacologic interventions to alleviate depressive and anxiety symptoms may be needed.

Caregivers and family members are also adversely affected by a diagnosis of mesothelioma. In a qualitative study, patients described that the disease negatively impacted the spousal relationship, invoked anger and frustration, and resulted in caregiver burden.<sup>76</sup> Another study found that caregivers who were primarily women over age 50 years identified perceptions of personal inefficacy and helplessness,

lowered trust, and heightened fear that impacted their regular activities.<sup>75</sup> It is essential that nurses assess the needs of the caregiver, and that the potential need for respite care is addressed.<sup>23</sup>

As the disease progresses, patients may have increasing concerns related to loss of roles, finances, about who will care for family members after their death, being a burden on family members, and about death and dying. Patients may also have spiritual and existential concerns, including questions about the meaning and purpose of life. Religious and cultural traditions and beliefs may also become increasingly important.<sup>69</sup>

## Physical symptoms

Similar to patients with other types of malignant and progressive pulmonary pathology, patients with mesothelioma often experience dyspnea.<sup>77</sup> Dyspnea, a subjective multifactorial experience of breathlessness, varies in severity and influence on a patient's well-being.<sup>77</sup> Dyspnea assessment should include a thorough history consisting of physical, psychological, and social impact, along with an objective physical assessment.<sup>77</sup> Such assessment tools as the visual analog scale may be helpful, particularly to assess the effectiveness of interventions to reduce dyspnea.<sup>77</sup>

Patients who have pleural effusions and lung-shunt effects may have symptomatic palliation of dyspnea and shortness of breath from chemical (introduction of chemical agents; bleomycin, slurry of talc and other agents into pleural space) pleurodesis following thoracoscopic fluid drainage.<sup>8,16,40</sup> Pleurodesis is considered effective if no further fluid drainage is needed following the procedure.<sup>78</sup> In a large-scale study (n=494 patients), pleurodesis was required for 42% of the patients, less than 30% of the patients achieved complete effusion control, and 32% required repeat procedures.<sup>78</sup> For patients who are not eligible for pleurodesis, surgical pleuroectomy with en bloc removal of the parietal and visceral pleura can serve to prevent pleural effusion.<sup>8</sup>

Importantly, dyspnea has strong cognitive and affective components, and can be exacerbated by existential fears, concerns about treatment, and other stressors.<sup>77</sup> Management of dyspnea may include cognitive behavioral therapy and medications such as benzodiazepines and opioids to alleviate anxiety.<sup>69</sup> Such opioids as morphine sulfate may also lessen the perception of dyspnea.<sup>69</sup> Patients who are hypoxic often need supplemental oxygen therapy, and may benefit from nasal airflow and fans.<sup>69,77</sup>

Pain can result from tumor infiltration of the intercostal nerves, resulting in neuropathic pain syndromes.<sup>69</sup>

Patients who have had surgery, including pleurectomy or extrapleural pneumonectomy, may develop neuropathic post-thoracotomy pain syndromes and hyperesthesias that make even light touch severely painful in the area of the surgery. Further, such chemotherapeutic agents as cisplatin can cause painful peripheral neuropathies.<sup>69</sup> Patients who receive radiation therapy may experience radiation pneumonitis and short-term pain with swallowing.<sup>31</sup>

Comprehensive and ongoing pain assessment and management is a critical nursing initiative to promote quality of life for patients.<sup>79</sup> Neuropathic pain may be managed pharmacologically with corticosteroids, anticonvulsants, tricyclic antidepressants, and  $\alpha 2$  agonists.<sup>40</sup> Opioids may be strategic in the management of pain, but individualized tailoring of dosing toward pain severity, personal needs, and tolerance is essential to achieve effectiveness.<sup>79</sup> Further, opioids carry such side effects as constipation, nausea, and sedation, and thus require close monitoring by the health care team. Effective pain management may include lidocaine patches, nerve blocks, and insertion of epidural or intrathecal catheters to administer medications.<sup>69</sup> Cordotomy, a surgical procedure that interrupts pain-conducting neural tracts in the spinal cord resulting in the loss of pain perception, can be used when other pain strategies are not effective. While there is little research that has examined the role of complementary therapies, such as mindfulness meditation, guided imagery, and relaxation strategies, in this population, these methods have been used for other cancer groups, and could be considered if patients are interested.<sup>80</sup>

Fatigue is also a significant and relatively common experience for mesothelioma patients.<sup>3,70</sup> Fatigue levels also increase over time with disease progression, and may be a consequence of aggressive medical management.<sup>32</sup> Fatigue may also accompany emotional distress, insomnia, and excessive stress. Pulmonary rehabilitation that involves physical exercises has been shown to have positive effects in cancer patients who also have pulmonary symptoms.<sup>81</sup> Little research has examined nursing interventions to combat fatigue in mesothelioma patients. Nurses may discuss energy-conservation strategies with patients, assess nutritional status, and explore underlying factors for fatigue occurrence.

## Palliative care

Palliative care emphasizes a multidisciplinary approach to the management of patients.<sup>82</sup> The aims of palliative care are to provide symptom relief, promote quality of life, and offer support during any point in the survivorship trajectory of a life-limiting illness.<sup>82</sup> Nursing initiatives to coordinate palliative

care referrals following diagnosis to ensure optimal symptom management and emotional support are recommended.<sup>72</sup> If early palliative care is not initiated, health care providers may maintain a short-term perspective and focus only on acute treatment issues.<sup>72</sup> It is essential that patients who are receiving ongoing treatment aimed at prolonging life also receive coincident supportive care aimed at fostering quality of life. For example, medical treatments can be scheduled to avoid conflict with family events and important holidays. Further, the need for open and honest communication about the costs and benefits of pursuing and/or stopping life-sustaining treatment should occur in the context of a therapeutic relationship that is developed over time.

In the UK, evidence demonstrating a lack of specific mesothelioma services led to the development of the Mesothelioma Framework in 2007.<sup>4</sup> The framework provides specific guidelines relative to organizing mesothelioma services to improve care for patients suffering from mesothelioma.<sup>4</sup> The guideline recommendations included the provision of a nurse clinician who specializes in mesothelioma care and organizes a multidisciplinary team, coordinates care over time, and responds to patient/family concerns, including informational needs and guidance.<sup>4</sup> In line with the Mesothelioma Framework, a Mesothelioma Nurse Action Team was created to organize a network of mesothelioma nurses who engage in networking and collaboration to develop best practice to improve the care of mesothelioma patients in the UK.<sup>4</sup>

## End-of-life care

As patients near the end of life, the hospice team can be an essential resource to the patient and family, providing education and support.<sup>69</sup> Social work, chaplain services, and support from psychiatric services may also be consulted. Hospice services may range from continuous nursing in an inpatient setting to home visits, around-the-clock on-call services, and respite care. The goals for respite care are to provide caregiver support and rest, or to place the patient in an alternative environment if home care is not adequate on a short-term basis.

Patients may want to initiate discussions about death. Both patients and their families may experience anticipatory loss and grief as the reality of impending death becomes more apparent. In addition, it can be difficult for health providers to acknowledge their own painful emotions, such as sadness and perceptions of inadequacy. Acknowledgment of these emotions with the facilitation of open discussion among members of the multidisciplinary team relative to this process may assist in managing these challenges.

## Advocacy

It is essential that all patients suspected of having mesothelioma have a thorough evaluation of their occupational history.<sup>8</sup> Patients may desire assistance with filing claims and interpreting potential benefits to gain needed compensation relative to the disease.<sup>3</sup> If patients have to travel long distances for optimal medical management, there may be logistical issues associated with finances, lodging for family members, and other expenses.<sup>23</sup> Given the length of the latency period between exposure to asbestos and the development of mesothelioma, patients may not always recall when/where in their work life this carcinogen encounter occurred.<sup>47</sup>

Nurses can provide patients with resources from such advocacy organizations as the Mesothelioma Center (<http://www.asbestos.com>) and the Mesothelioma Cancer Alliance (<http://www.mesothelioma.com>). These organizations offer information about the disease and treatment, doctors and treatment centers that offer specialty care, veteran's services, legal options, and patient-support groups. Patients and their family may feel less alone and even empowered by connecting with others who are facing a similar ordeal.

## Future nursing research

Given the severity and complexity of care required for patients with pleural mesothelioma, there remains limited comparative research that has examined the patient's perspective over the trajectory of this illness. Many studies that have examined patient and caregiver issues have had small samples and are qualitative in nature. Much of the quality-of-life research has been conducted with patients who are participating in clinical trial studies. While the existing research has made strong contributions to optimizing knowledge of the unique experiences of pleural mesothelioma patients, nursing studies that capture social well-being, illness perceptions including trajectory-specific disease and type of treatment-related symptoms, self-efficacy relative to illness and treatment management, and patient coherence and preference of treatment options are needed.

## Conclusion

Despite years of ongoing research and development, malignant pleural mesothelioma remains a severe life-threatening disease that carries a poor prognosis and places a huge burden on affected patients and their family members.<sup>1</sup> Therefore, treatment goals are largely to improve quality of life, manage symptoms, and prolong life, as there is no cure for this aggressive disease.<sup>8</sup> It is evident that mesothelioma

care is widely varied depending on access to specialized multidisciplinary care and clinical trials. Nurses as patient advocates can promote the patient's and their loved ones' ability to negotiate the many challenges that are part of the mesothelioma survivorship trajectory via coordination of holistic multidisciplinary care, ensuring that the patient has access to up-to-date resources and information and optimizing symptom management. It is apparent that integration of acute disease-oriented care and palliative care is of critical importance to ensure that patients with pleural mesothelioma receive comprehensive and optimal treatment over their illness continuum.

## Disclosure

The author reports no conflicts of interest in this work.

## References

1. van Meerbeeck JP, Scherpereel A, Surmont VF, Baas P. Malignant pleural mesothelioma: the standard of care and challenges for future management. *Crit Rev Oncol Hematol*. 2011;78:92–111.
2. Brims FJ, Maskell NA. Prognostic factors for malignant pleural mesothelioma. *Curr Respir Care Rep*. 2013;2:100–108.
3. Moore S, Darlison L, Tod AM. Living with mesothelioma: a literature review. *Eur J Cancer Care*. 2010;19:458–468.
4. Moore S, Darlison L. Improving the nursing care of patients with mesothelioma. *Nurs Stand*. 2011;25:35–38.
5. Thompson JK, Westbom CM, Shukla A. Malignant mesothelioma: development to therapy. *J Cell Biochem*. 2014;115:1–7.
6. Tagawa M, Tada Y, Shimada H, Hiroshima K. Gene therapy for malignant mesothelioma: current prospects and challenges. *Cancer Gene Ther*. 2013;20:150–156.
7. Campbell NP, Kindler HL. Update on malignant pleural mesothelioma. *Semin Respir Crit Care Med*. 2011;32:102–110.
8. Neumann V, Löseke S, Nowak D, Herth FJ, Tannapfel A. Malignant pleural mesothelioma: incidence, etiology, diagnosis, treatment, and occupational health. *Dtsch Arztebl Int*. 2013;110:319–326.
9. Okello C, Treasure T, Nicholson AG, Peto J, Möller H. Certified causes of death in patients with mesothelioma in South East England. *BMC Cancer*. 2009;9:28.
10. Chen SE, Pace MB. Malignant pleural mesothelioma. *Am J Health Syst Pharm*. 2012;69:377–385.
11. Carbone M, Ly BH, Dodson RF, et al. Malignant mesothelioma: facts, myths and hypotheses. *J Cell Physiol*. 2012;227:44–58.
12. Tsao AS, Wistuba I, Roth JA, Kindler HL. Malignant pleural mesothelioma. *J Clin Oncol*. 2009;27:2081–2090.
13. Pass HI, Carbone M. Current status of screening for malignant pleural mesothelioma. *Semin Thorac Cardiovasc Surg*. 2009;21:97–104.
14. Greillier L, Astoul P. Mesothelioma and asbestos-related pleural diseases. *Respiration*. 2008;76:1–15.
15. Hasegawa S. Early mesothelioma revisited. *Int J Clin Oncol*. 2012;17:30–32.
16. Mott FE. Mesothelioma: a review. *Ochsner J*. 2012;12:70–79.
17. Steer J, Bough G, Razak AR, Meachery GJ, Hughes A. Life after first-line chemotherapy in malignant pleural mesothelioma: a North-East England experience. *Clin Oncol (R Coll Radiol)*. 2010;22:231–235.
18. Hollen PJ, Gralla RJ, Liepa AM, Symanowski JT, Rusthoven JJ. Measuring quality of life in patients with pleural mesothelioma using a modified version of the Lung Cancer Symptom Scale (LCSS): psychometric properties of the LCSS-Meso. *Support Care Cancer*. 2006;14:11–21.
19. Goudar RK. Management options for malignant pleural mesothelioma: clinical and cost considerations. *Drugs*. 2007;67:1149–1165.

20. Nowak AK, Bydder S. Management of malignant pleural mesothelioma. *Asia Pac J Clin Oncol*. 2007;3:177–186.
21. Ambrogi V, Mineo D, Gatti A, Pompeo E, Mineo TC. Symptomatic and quality of life changes after extrapleural pneumonectomy for malignant pleural mesothelioma. *J Surg Oncol*. 2009;100:199–204.
22. Lee CW, Martin J, MacRae R, et al. Malignant mesothelioma: Canadian perspective and research directions. *Curr Oncol*. 2008;15:104–111.
23. Lee SF, O'Connor MM, Chapman Y, Hamilton V, Francis K. A very public death: dying of mesothelioma and asbestos-related lung cancer (M/ARLC) in the Latrobe Valley, Victoria, Australia. *Rural Remote Health*. 2009;9:1183.
24. Flores RM, Riedel E, Donington JS, et al. Frequency of use and predictors of cancer-directed surgery in the management of malignant pleural mesothelioma in a community-based (Surveillance, Epidemiology, and End Results [SEER]) population. *J Thorac Oncol*. 2010;5:1649–1654.
25. Greillier L, Bass P, Welch JJ, Hasan B, Passiukov A. Biomarkers for malignant pleural mesothelioma: current status. *Mol Diagn Ther*. 2008;12:375–390.
26. Chiriac LR, Corson JM. Pathologic evaluation of malignant pleural mesothelioma. *Semin Thorac Cardiovasc Surg*. 2009;21:121–124.
27. Baas P. Optimising survival in malignant mesothelioma. *Lung Cancer*. 2007;57 Suppl 2:S24–S29.
28. Bueno R. Making the case for molecular staging of malignant pleural mesothelioma. *Semin Thorac Cardiovasc Surg*. 2009;21:188–193.
29. Waite K, Gilligan D. The role of radiotherapy in the treatment of malignant pleural mesothelioma. *Clin Oncol (R Coll Radiol)*. 2007;19:182–187.
30. Fuhrer G, Lazarus AA. Mesothelioma. *Dis Mon*. 2011;57:40–54.
31. Jenkins P, Milliner R, Salmon C. Re-evaluating the role of palliative radiotherapy in malignant pleural mesothelioma. *Eur J Cancer*. 2011;47:2143–2149.
32. Mollberg NM, Vigneswaran Y, Kindler HL, et al. Quality of life after radical pleurectomy decortication for malignant pleural mesothelioma. *Ann Thorac Surg*. 2012;94:1086–1093.
33. Suzuki H, Asami K, Hirashima T, et al. Stratification of malignant pleural mesothelioma prognosis using recursive partitioning analysis. *Lung*. 2014;192:191–195.
34. Palmer C, Thain C. Strategies to ensure effective and empathetic delivery of bad news. *Cancer Nurs Pract*. 2010;9:24–27.
35. Bölükbas S, Manegold C, Eberlein M, Bergmann T, Fisseler-Eckhoff A, Schirren J. Survival after trimodality therapy for malignant pleural mesothelioma: Radical pleurectomy, chemotherapy with cisplatin/pemetrexed and radiotherapy. *Lung Cancer*. 2011;71:75–81.
36. Su S. Mesothelioma: path to multimodality treatment. *Semin Thorac Cardiovasc Surg*. 2009;21:125–131.
37. Jackman DM. Current options for systemic therapy in mesothelioma. *Semin Respir Crit Care Med*. 2009;21:154–158.
38. Ribí K, Bernhard J, Schuller JC, et al. Individual versus standard quality of life assessment in a phase II clinical trial in mesothelioma patients: feasibility and responsiveness to clinical changes. *Lung Cancer*. 2008;61:398–404.
39. Ettinger DS, Akerley W, Borghaei H, et al. Malignant pleural mesothelioma. *J Natl Cancer Compr Canc Netw*. 2012;10:26–41.
40. van Thiel E, Gaafar R, van Meerbeeck JP. European guidelines for the management of malignant pleural mesothelioma. *J Advanc Res*. 2011;2:281–288.
41. Kaufman AJ, Flores RM. Surgical treatment of malignant pleural mesothelioma. *Curr Treat Options Oncol*. 2011;12:201–216.
42. Wolf AS, Daniel J, Sugarbaker DJ. Surgical techniques for multimodality treatment of malignant pleural mesothelioma: extrapleural pneumonectomy and pleurectomy. *Semin Thorac Cardiovasc Surg*. 2009;21:132–148.
43. Rena O, Casadio C. Extrapleural pneumonectomy for early stage malignant pleural mesothelioma: a harmful procedure. *Lung Cancer*. 2012;77:151–155.
44. Ploenes T, Osei-Agyemang T, Krohn A, et al. Changes in lung function after surgery for mesothelioma. *Asian Cardiovasc Thorac Ann*. 2012;21:48–55.
45. Treasure T, Lang-Lazdunski L, Waller D, et al. Extra-pleural pneumonectomy versus no extra-pleural pneumonectomy for patients with malignant pleural mesothelioma: clinical outcomes of the Mesothelioma and Radical Surgery (MARS) randomised feasibility study. *Lancet Oncol*. 2011;12:763–772.
46. Sharif S, Zahid I, Routledge T, Scarci M. Extrapleural pneumonectomy or supportive care: treatment of malignant pleural mesothelioma? *Interact Cardiovasc Thorac Surg*. 2011;12:1040–1045.
47. Moore AJ, Parker RJ, Wiggins J. Malignant mesothelioma. *Orphanet J Rare Dis*. 2008;3:34.
48. Lee C, Bayman N, Swindell R, Faivre-Finn C. Prophylactic radiotherapy to intervention sites in mesothelioma: a systematic review and survey of UK practice. *Lung Cancer*. 2009;66:150–156.
49. Froment M, Frechette E, Dagnautl A. Prophylactic irradiation of intervention sites in malignant pleural mesothelioma. *Radiother Oncol*. 2011;101:307–310.
50. Baldini EH. Radiation therapy options for malignant pleural mesothelioma. *Semin Thorac Cardiovasc Surg*. 2009;21:159–163.
51. Quispel-Janssen JM, Baas P. Emerging therapies for malignant pleural mesothelioma. *Curr Respir Care Rep*. 2012;1:91–100.
52. Garland LL. Chemotherapy for malignant pleural mesothelioma. *Curr Treat Options Oncol*. 2011;12:181–188.
53. Ceresoli GL, Zucali PA, Gianoncelli L, Lorenzi E, Santoro A. Second-line treatment for malignant pleural mesothelioma. *Cancer Treat Rev*. 2010;36:24–32.
54. Metintas M, Ak G, Erginel S, et al. A retrospective analysis of malignant pleural mesothelioma patients treated either with chemotherapy or best supportive care between 1990 and 2005: a single institution experience. *Lung Cancer*. 2007;55:379–387.
55. Stahel RA. Malignant pleural mesothelioma: a new standard of care. *Lung Cancer*. 2006;54 Suppl 2:S9–S14.
56. Kao SC, van Zandwijk N, Corte P, Clarke C, Clarke S, Vardy J. Use of cancer therapy at the end of life in patients with malignant pleural mesothelioma. *Support Care Cancer*. 2013;21:1879–1884.
57. Weder W, Opitz I, Stahel R. Multimodality strategies in malignant pleural mesothelioma. *Semin Thorac Cardiovasc Surg*. 2009;21:172–176.
58. Flores RM. Surgical options in malignant pleural mesothelioma: extrapleural pneumonectomy or pleurectomy/decortication. *Semin Thorac Cardiovasc Surg*. 2009;21:149–153.
59. Zauderer MG, Krug LM. The evolution of multimodality therapy for malignant pleural mesothelioma. *Curr Treat Options Oncol*. 2011;12:163–172.
60. Stahel RA, Felley-Bosco E, Opitz I, Weder W. Malignant pleural mesothelioma. *Future Oncol*. 2009;5:391–402.
61. Tonoli S, Vitali P, Scotti V, et al. Adjuvant radiotherapy after extrapleural pneumonectomy for mesothelioma. Prospective analysis of a multi-institutional series. *Radiother Oncol*. 2011;101:311–315.
62. Surmont VF, van Thiel ER, Vermaelen K, van Meerbeeck JP. Investigational approaches for mesothelioma. *Front Oncol*. 2011;1:1–15.
63. Mossman BT, Shukla A, Heintz NH, Verschraegen CF, Thomas A, Hassan R. New insights into understanding the mechanisms, pathogenesis, and management of malignant mesotheliomas. *Am J Pathol*. 2013;182:1065–1077.
64. Whitson BA, Kratzke RA. Molecular pathways in malignant pleural mesothelioma. *Cancer Lett*. 2006;239:183–189.
65. Ali G, Boldrini L, Lucchi M, et al. Treatment with interleukin-2 in malignant pleural mesothelioma: immunological and angiogenetic assessment and prognostic impact. *Br J Cancer*. 2009;101:1869–1875.
66. Buikhusien WA, Burgers JA, Vincent AD, et al. Thalidomide versus active supportive care for maintenance in patients with malignant mesothelioma after first-line chemotherapy (NVALT 5): an open-label, multicentre, randomised phase 3 study. *Lancet Oncol*. 2013;14:543–551.
67. Friedberg JS. Photodynamic therapy for malignant pleural mesothelioma: the future of treatment? *Expert Rev Respir Med*. 2011;5:49–63.
68. Vachani A, Moon E, Albelda SM. Gene therapy for mesothelioma. *Curr Treat Options Oncol*. 2011;12:173–180.



69. Abraham JL. Palliative care for the patient with mesothelioma. *Semin Thorac Cardiovasc Surg.* 2009;21:164–171.
70. Muers MF, Stephens RJ, Fisher P, et al. Active symptom control with or without chemotherapy in the treatment of patients with malignant pleural mesothelioma (MS01): a multicentre randomised trial. *Lancet.* 2008;371:1685–1694.
71. Kao SC, Vardy J, Harvie R, et al. Health-related quality of life and inflammatory markers in malignant pleural mesothelioma. *Support Cancer Care.* 2013;21:697–705.
72. Arber A, Spencer L. 'It's all bad news': the first 3 months following a diagnosis of malignant pleural mesothelioma. *Psychooncology.* 2013;22:1528–1533.
73. Moore S, Teehan C, Cornwall A, Ball K, Thomas J. 'Hands of Time': the experience of establishing a support group for people affected by mesothelioma. *Eur J Cancer Care.* 2008;17:585–592.
74. Dooley JJ, Wilson JP, Anderson VA. Stress and depression of facing death: investigation of psychological symptoms in patients with mesothelioma. *Aust J Psychol.* 2010;62:160–168.
75. Granieri A, Tamburello S, Tamburello A, et al. Quality of life and personality traits in patients with malignant pleural mesothelioma and their first-degree caregivers. *Neuropsychiatr Dis Treat.* 2013;9:1193–1202.
76. Hughes N, Arbor A. The lived experience of patients with pleural mesothelioma. *Int J Palliat Nurs.* 2008;14:66–71.
77. Thomas S, Bausewein C, Higginson I, Booth S. Breathlessness in cancer patients: implications, management and challenges. *Eur J Oncol Nurs.* 2011;15:459–469.
78. Fysh ET, Tan SK, Read CA, et al. Pleurodesis outcome in malignant pleural mesothelioma. *Thorax.* 2013;68:594–596.
79. Salminen EK, Silvonieni M, Syrjänen K, Kaasa S, Kloke M, Klepstad P. Opioids in pain management of mesothelioma and lung cancer patients. *Acta Oncol.* 2013;52:30–37.
80. Robotin M, Holliday C, Bensoussan A. Defining research priorities in complementary medicine in oncology. *Complement Ther Med.* 2012;20:345–352.
81. Morris GS, Gallagher GH, Baxter MF, et al. Pulmonary rehabilitation improves functional status in oncology patients. *Arch Phys Med Rehabil.* 2009;90:837–841.
82. Bakitas M, Bishop MF, Caron P, Stephens L. Developing successful models of cancer palliative care services. *Semin Oncol Nurs.* 2010;26:266–284.

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