



Palliative care for people living with asbestos related diseases

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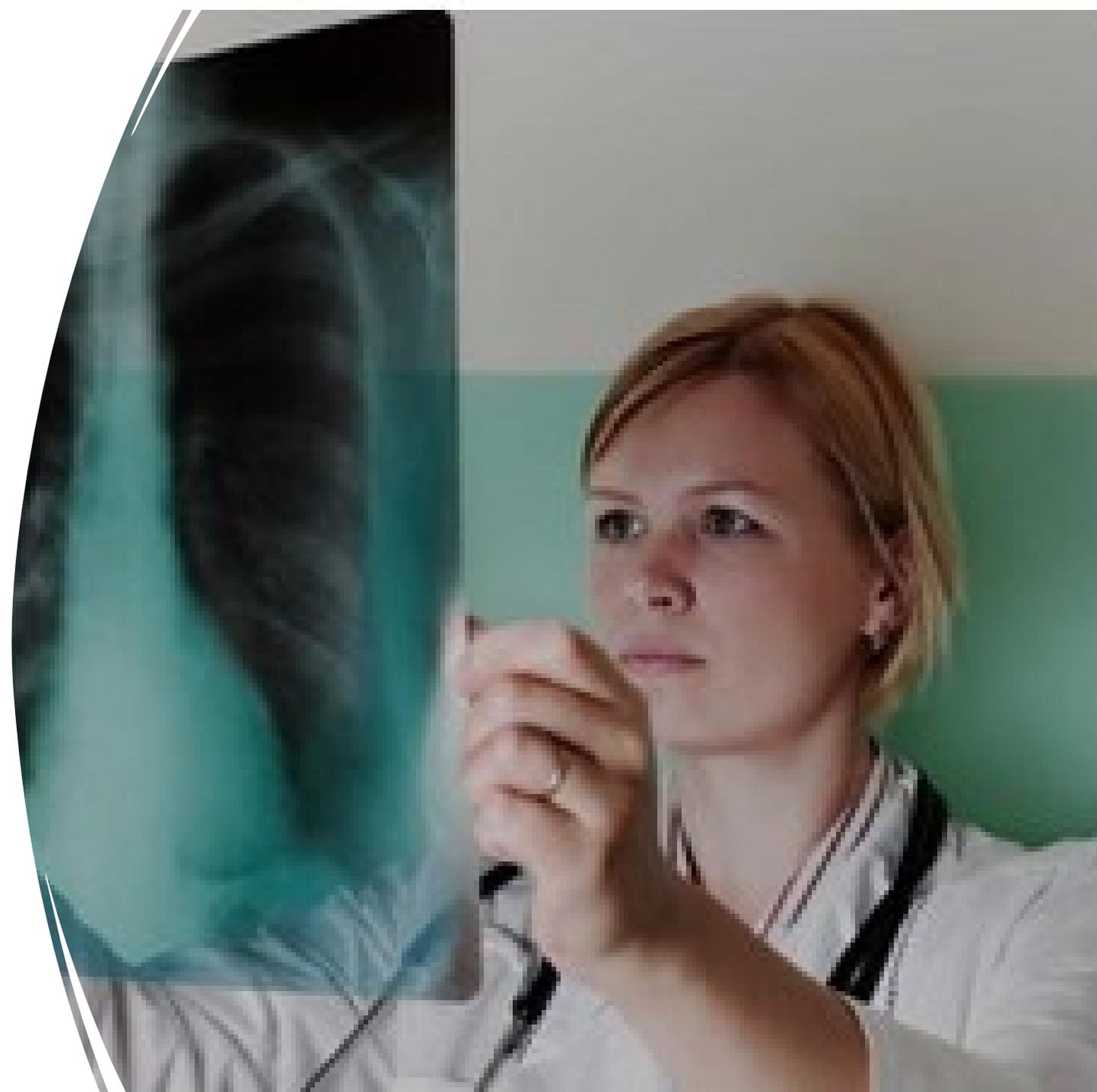
Asbestos related disease

- To focus on malignant mesothelioma
- Many symptoms and emotional/social/existential issues related to asbestosis, lung cancer, pleural fibrosis respond to the palliative interventions described in this talk
- Palliative care – the relief of suffering in serious illness whatever the diagnosis



Mesothelioma

- Rare cancer
- High symptom burden
- Limited survival
- Important to include palliative care services once the diagnosis is made
- Important for the care team, including oncology team, to be skilled in providing palliative care



Palliative care goals

Improve quality of life for people living with life-threatening illness;

Provides relief from pain and other distressing symptoms;

Integrates the psychological and spiritual aspects of patient care;

Offers a support system to help patients live as actively as possible until death;



Palliative care goals

- Offers a support system to help the family cope during the patient's illness and in their bereavement;
- Is applicable early in the course of illness, in conjunction with other therapies.

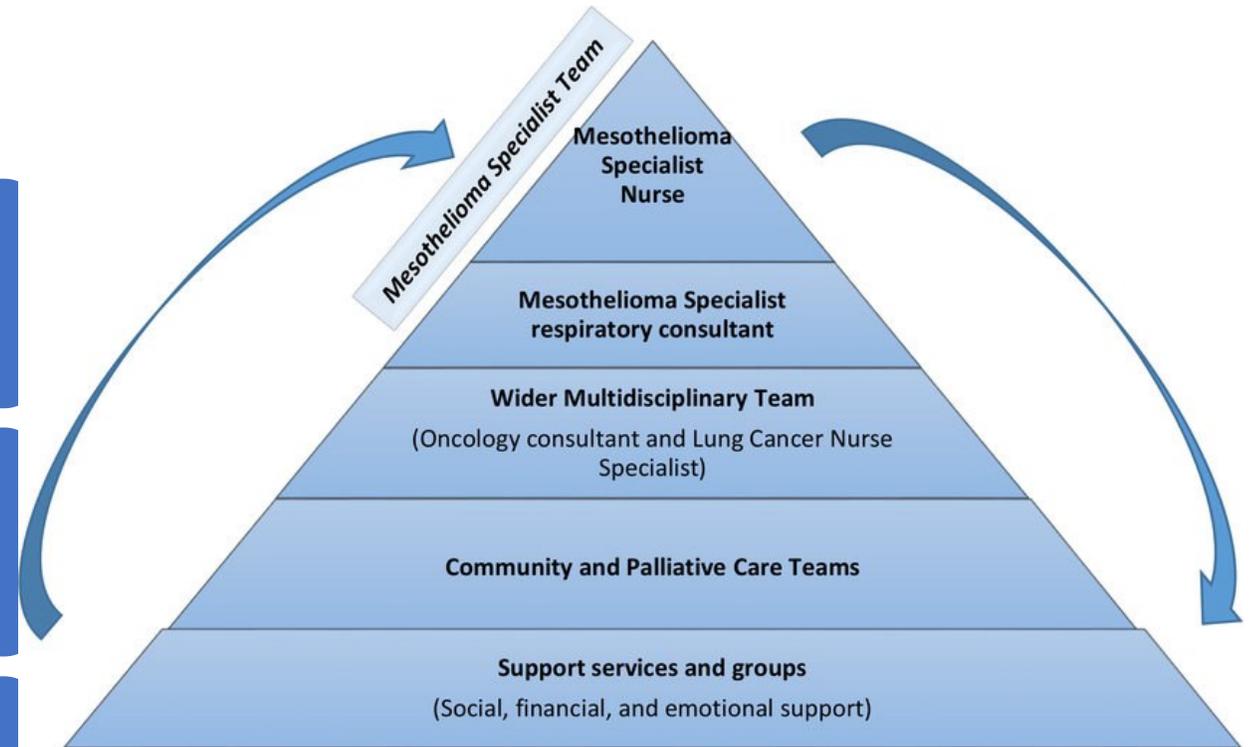


Palliative care focus

Needs of people living with mesothelioma and their families

Support for colleagues caring for these patients

Palliative care best provided through multidisciplinary team



Palliative care needs of people with mesothelioma & their families

- Systematic review described overarching theme of ‘uncertainty’
- Subthemes:
 1. Organisation and co-ordination of services
 2. Communication and information needs
 3. Management of care needs and high symptom burden
 4. Consideration of impact of seeking compensation
 5. Family carer needs



Harrison M, Gardiner C, Taylor B, Ejegi-Memeh S, Darlison L. Understanding the palliative care needs and experiences of people with mesothelioma and their family carers: An integrative systematic review. *Palliative medicine*. 2021 Apr 8:02692163211007379.

Communication and information sharing

- Clinicians may be more comfortable discussing treatment options, and avoid difficult emotional topics
- We need to develop communication skills to engage in difficult discussions, to put aside our own discomfort and have the courage to listen to our patients' concerns
- We can provide factual information to the extent wanted by the patient that will assist people to make informed decisions and assist their choices for care and how they would like to spend what time they have left to them.
- We need to understand their fears and feelings so that we can address unrealistic fears and reassure them and explain what can be done to address realistic fears

Communication skills needed

- Overcoming own discomfort in addressing difficult issues
- Conducting family meetings
- Counselling those with emotional/existential distress
- Helping people cope with anger and grief
- Care planning in accordance with patients' preferences and choices
- Building hope - realistic hope



Building hope

- People may initially express hope for cure
- Hope changes with circumstances
- Hope for time
- Hope to be healthy enough to achieve goals and take part in important activities



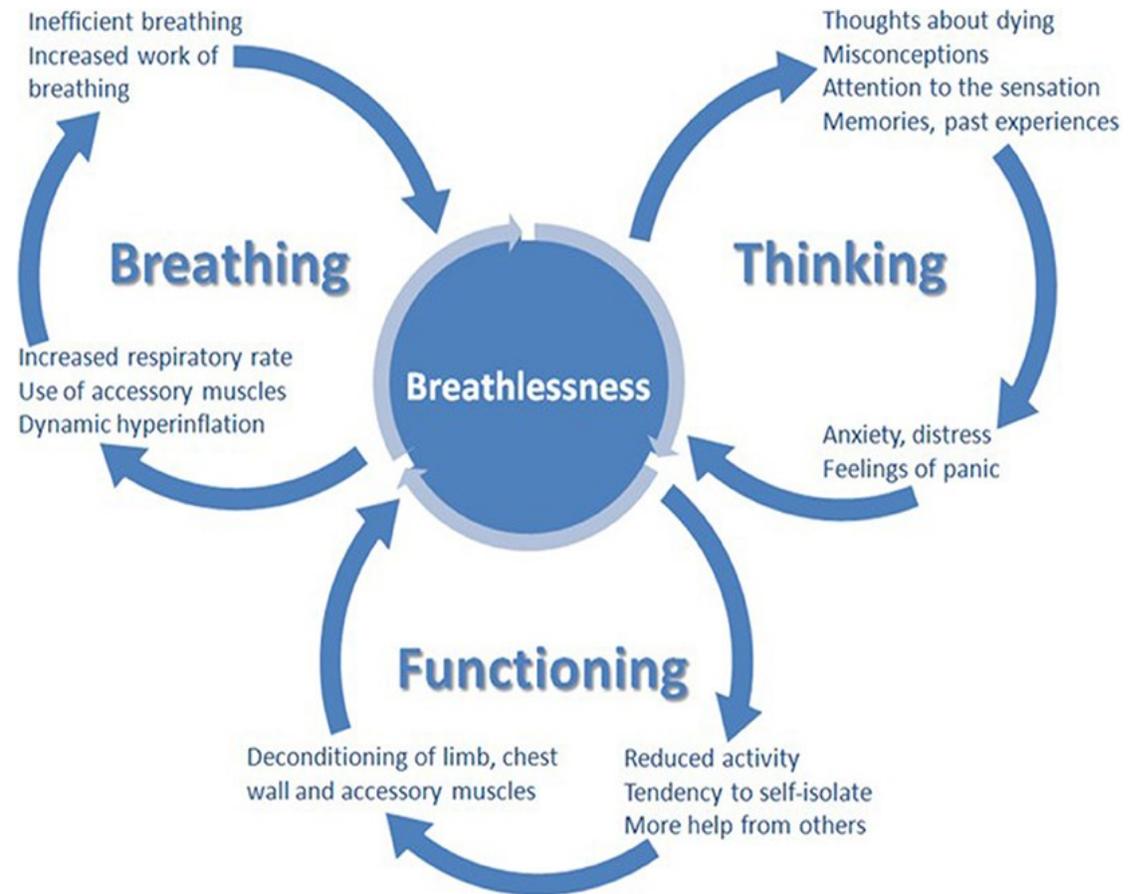
Building hope

- Hope for support and care for family members/compensation
- NB care team available, commit to non-abandonment
- Hospice team skilled in providing palliative care & provide this care in the patient's own home



Symptom control

- Most common symptoms: shortness of breath, tiredness, pain, worry, cough
- Shortness of breath opioids, anxiolytics; non-drug measures – attention to anxiety aggravating shortness of breath, flow of air across the face
- Depression and anxiety – counselling and medication
- Cough – assess and treat cause, opioids as cough suppressant



Abrahm JL. Palliative care for the patient with mesothelioma. In Seminars in thoracic and cardiovascular surgery 2009 Jun 1 (Vol. 21, No. 2, pp. 164-171). WB Saunders.

Pain control



- Pain – complex problem in mesothelioma requiring careful assessment and management, often neuropathic pain (due to damage to nerves) in addition to pain caused by tissue damage and inflammation
- Basic pain control – opioids combined with paracetamol, and short-term courses of anti-inflammatory meds
- Indwelling epidural catheter for patient-controlled analgesia
- Meds for neuropathic pain – gabapentin, corticosteroids, clonidine, duloxetine
- Anaesthetic techniques

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Social and spiritual/existential concerns

- Financial, compensation
- Loss of health
- Loss of anticipated future
- Loss of roles in family and community
- Loss of control
- Making meaning of lives and illness
- Social worker and spiritual counsellor can assist, helping people to discuss these issues and find some resolution of their concerns



Role of advocates for people living with mesothelioma

- Call for all health care workers to be trained in palliative care
- Call for specialists in palliative care for complex problems many of which affect people living with mesothelioma
- Call for availability of essential palliative care medicines
- Call for availability and accessibility of palliative care services
- Support for people living with mesothelioma & ARD and their families throughout the illness and for care to be provided at home



Thank you

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