

Palliative care in mesothelioma

-the management of pain & breathlessness

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Definition of palliative care

The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social, and spiritual problems, is paramount. The goal of palliative care is achievement of the best quality of life for patients and families."

World Health Organisation 1990

Mesothelioma in the UK

- 2300+ deaths pa in UK
(= 1 case of asbestos-related lung cancer for every mesothelioma + >400 asbestosis deaths)
- ~90% known asbestos exposure
- Male/female ratio = 6:1
- Average age at diagnosis: 69
- Latency – 30-50 years
- Diagnosis to death: < 10 months
- High risk now: construction/maintenance tradesmen eg joiners, electricians, plumbers

'The experience of pleural mesothelioma in Northern England'

A doctoral, community-based, mixed methods, 4-part, case study in 3 locations in Northern England: Barrow-in-Furness, Leeds and Doncaster – from the perspectives of palliative care and social medicine

Clayson H (2007) Doctoral thesis, University of Sheffield

Study locations



Study design

- Semi-structured interviews with 15 patients
- 6 focus groups with bereaved relatives
- Interviews with 11 healthcare professionals
- Review of GP, hospital and hospice records of 80 patients who had died with pleural mesothelioma (1998-2001)

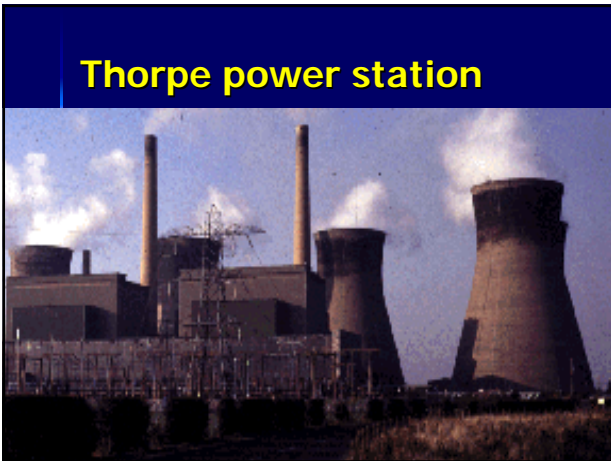
Barrow-in-Furness shipyard in the 1950s



The asbestos factory, Leeds



Thorpe power station



Doncaster railway plant works



Quantitative evidence of the symptom burden in mesothelioma

Sample: 53 with MPM, <76 years, ECOG PS 0-2, life expectancy >12 weeks, measurable disease and all receiving chemotherapy (cist/gem).

Results:

Overall symptom scores similar for MPM and NSCLC: 10 -20 points worse than normal population

Scores: **pain, role, & social functioning were ~ 10 points worse** in Mesothelioma than in Non Small Cell Lung Cancer – i.e. *'very much worse'* than in normal population.

Nowak AK, Stockler MR and Byrne MJ (2004) Assessing qol during chemotherapy for pleural mesothelioma: feasibility, validity and results of using the EORTC QOL-C30 and lung cancer module. *J Clin Oncol* 22:3172-3180.

Main themes from interviews with patients

1. Coping with symptoms
2. The burden of medical interventions
3. Finding out about mesothelioma
4. Psychosocial issues
5. State benefits and civil compensation claims

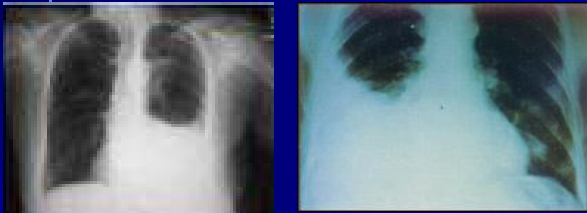
Recorded symptoms in pleural mesothelioma

Breathlessness	96%	Social	16%
Pain	91%	Nausea	14%
Cough	41%	Fatigue	13%
Weight loss	41%	Dysphagia	11%
Anxiety	31%	Psychiatric	10%
Anorexia	25%	Constipation	8%
Depression	19%	Ascites	8%
Sweating	18%	Vomiting	5%
Emotional	16%	Painful metastasis	5%

Breathlessness – quotes

- *'Fighting for breath', 'gasping for air', 'drowning in fluid', 'suffocating to death', 'out of control'* (patients)
- *'...and it sometimes gets real bad at night...and I've got to hang outside there, hang out of that window just so I can get some air.'* (Mr M: 79yr-old retired shipyard and railway worker, living alone)
- *'I know how bad my father got so I'm expecting the same'* (Mr G – his father died in severe distress due to mesothelioma)
- *'Terrifying to watch, I was helpless'* (Mrs T, bereaved carer)

Pleural effusions – in 78% cases



The experience of breathlessness

- A bio-psychosocial phenomenon
- Although hugely anxious, patients and relatives did not know when, or were reluctant, to call for help and often waited until desperate
- Crises caused fear of imminent death
- Breathlessness is visible, stigmatising and causes social isolation due to lack of mobility, loss of agency and embarrassment

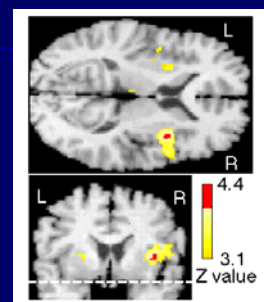
A new theory of perception

Perception is the 'brain's best guess' about what is happening in the outside world. The mind integrates scattered, weak, rudimentary signals from a variety of sensory channels, information from past experiences, and hard-wired processes, and produces a sensory experience full of brain-provided colour, sound, texture, and meaning...Perception is inference

(Atul Gawande, The itch. The New Yorker 30.6.2008)

- From CNS imaging study *'...central processing'* of breathlessness by higher centres is critical to modulating the severity of breathlessness.' (Banzett and Moosavi, 2001)
- Concept of 'total breathlessness' - similar to that of 'total pain' (Saunders 1967)

Cerebral activations by breathlessness (fPET)



Regions of increased rCBF with severe Air Hunger (n=8) super-imposed on typical structural MRI. (Banzett et al. 2000)

Breathlessness is not straightforward!

- Multiple aetiologies – not all physical
- No correlation between degree of perception of breathlessness and blood gas levels or respiratory rate
- No correlation between relief of breathlessness and physiological measurements
- Affects 12-74% terminally ill patients, 96% in mesothelioma
- The only reliable measurement is self-report
- 'It cannot be managed simply by 'stimulation of the failing organ' (Coats, 1998:130)

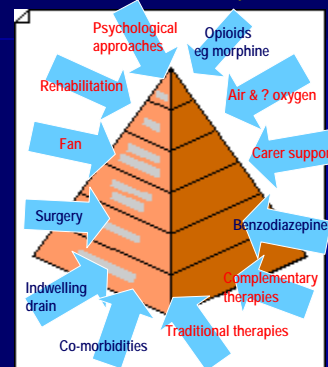
Invasive investigations and interventions



The benefits of an indwelling pleural drain



Multi-dimensional approach to breathlessness (after Ahmedzai and Clayton 2006)



Non-pharmacological interventions for breathlessness

- RCT of nursing intervention for breathlessness (Bredin, Corner et al, 1999, BMJ, 318: 901-4)
- BIS (Breathlessness intervention service) (Booth, Farquhar et al, 2006, Palliative and Supportive Care, 4, 287-93)
 - Complex bio-psychosocial intervention: assessment, goals, strategies, review, support
 - Aim to improve quality of life for patients and carers
 - Exercise and activity
 - Oxygen only of value if hypoxic
 - Hand-held fan

Use a (hand-held) fan



The movement of cool air with a fan has been observed to reduce dyspnoea in patients.

Stimulation of mechanoreceptors or temperature receptors mediated via the trigeminal nerve and may alter afferent feedback to the brain and modify the perception of dyspnoea.

Hand-held fans are preferred to static fans possibly because they promote a sense of mastery

(Schartzstein et al, 1987. Am Rev Resp Diseases 136: 58-61)

Palliation of pain

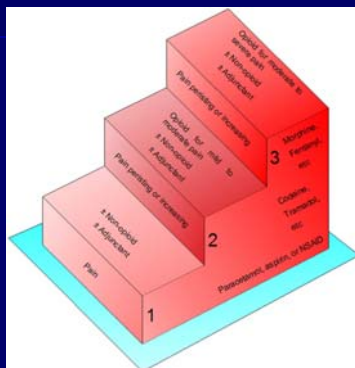
- Pain scores are higher in mesothelioma than in lung cancer (EORTC QLQ C30 in Nowak, Stockler, Byrne, 2004)
- 'Early involvement of a pain specialist is often needed' (BTS 2001) but only 49% referred and 2/3 within 8/52 of death
- High doses of opioids and adjuvants are required (Mercadante et al, 2001) but median dose 100mg oral morphine/day
- Treatment should be multi-faceted to address the cause/s of the pain (Ahmedzai and Clayton 2006) but *minimal* use of adjuncts and pain specialists revealed in the study

Pain in mesothelioma

'...good grief, violent pains... I had another day off, and that went away. Then ...Oh dear, I started with violent pains. I was jumping about on that settee like no-one's business, and Betty said "Get the doctor". I said "It'll go away, it went away last week, it'll be all right, it'll go away". She says "Get the doctor, we're not having that noise all day!"
Mr Y, 69yrs, retired engineer - shipyard, railway works and power station

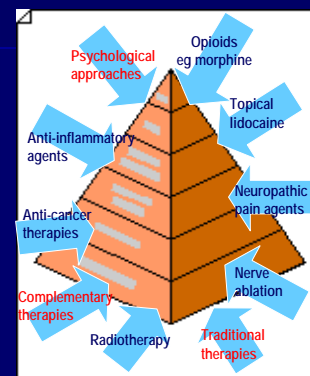
'... the pain's always there but I can control it with the medication, up to a point. It varies day by day, sometimes it'll pull in my back, other times it'll pull in my front, other times it'll pull where I had my biopsy - it's really nasty when it gets to that area.'
Mr T, 66 yrs, retired shop manager

The WHO analgesic ladder - 1989



The analgesia pyramid in mesothelioma

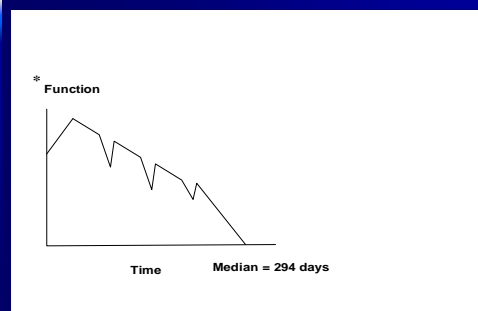
(After Ahmedzai, 2002)



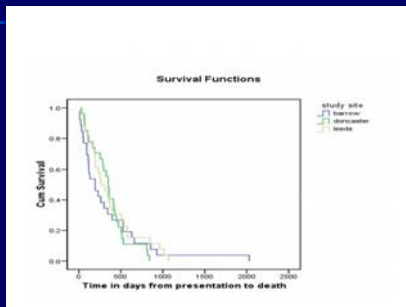
Pain control in mesothelioma

- Address psychological & social issues
- Use morphine first-line
- Add nerve pain agent if indicated
- Try non-steroidal anti-inflammatory agent
- Add 2nd nerve pain agent
- Consider either specialist management eg methadone, ketamine or nerve ablation procedure eg cordotomy.

Illustration of the disease trajectory



Survival curve



Psychosocial distress

- Anxiety pre- and post-diagnosis re the illness
- 'Damocles syndrome'
- Bad news broken badly
- Lack of effective treatments
- Invasive investigations and interventions
- Facing death
- Attribution/self-blame
- Contamination of family members
- Claims and benefits procedures
- Stoical accounts from patients contrast dramatically with bereaved relatives' accounts
- Medical nihilism often obvious

'It's mass murder isn't it?'

Highly emotional accounts from bereaved relatives:

- Persisting fury and outrage
- Betrayal by those in authority
- An 'orphan cancer': lack of medical & public knowledge
- Lack of information
- Social isolation
- Burden of care
- 'No closure' and tragic grief
- Later, maybe campaigning as a positive step

BARDS' activities



Conclusions

Mesothelioma is a **devastating disease** with severe burdens in physical, psychological and social domains.

Palliative care can relieve severe symptoms and distress in patients with mesothelioma and help their families cope.

Unrelieved suffering is a violation of a basic human right – *the right to the best possible state of health* – this extends to people who are dying.

We have the knowledge and skills to relieve suffering – the challenge is to deliver this care to all those who need it.

Proposal

Based on:

The knowledge that victims of asbestos-related diseases experience tragic and severe suffering, &

the evidence that palliative care can relieve a significant part of that suffering,

I would like this meeting to consider an addition to the ABAN campaign:

Palliative care services should be made available for all victims of asbestos related diseases.

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