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The experience of pleural mesothelioma in Northern England

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IOELC, Lancaster University

Helen Clayson
Jane Seymour
Peter Bath
Bill Noble

Outline

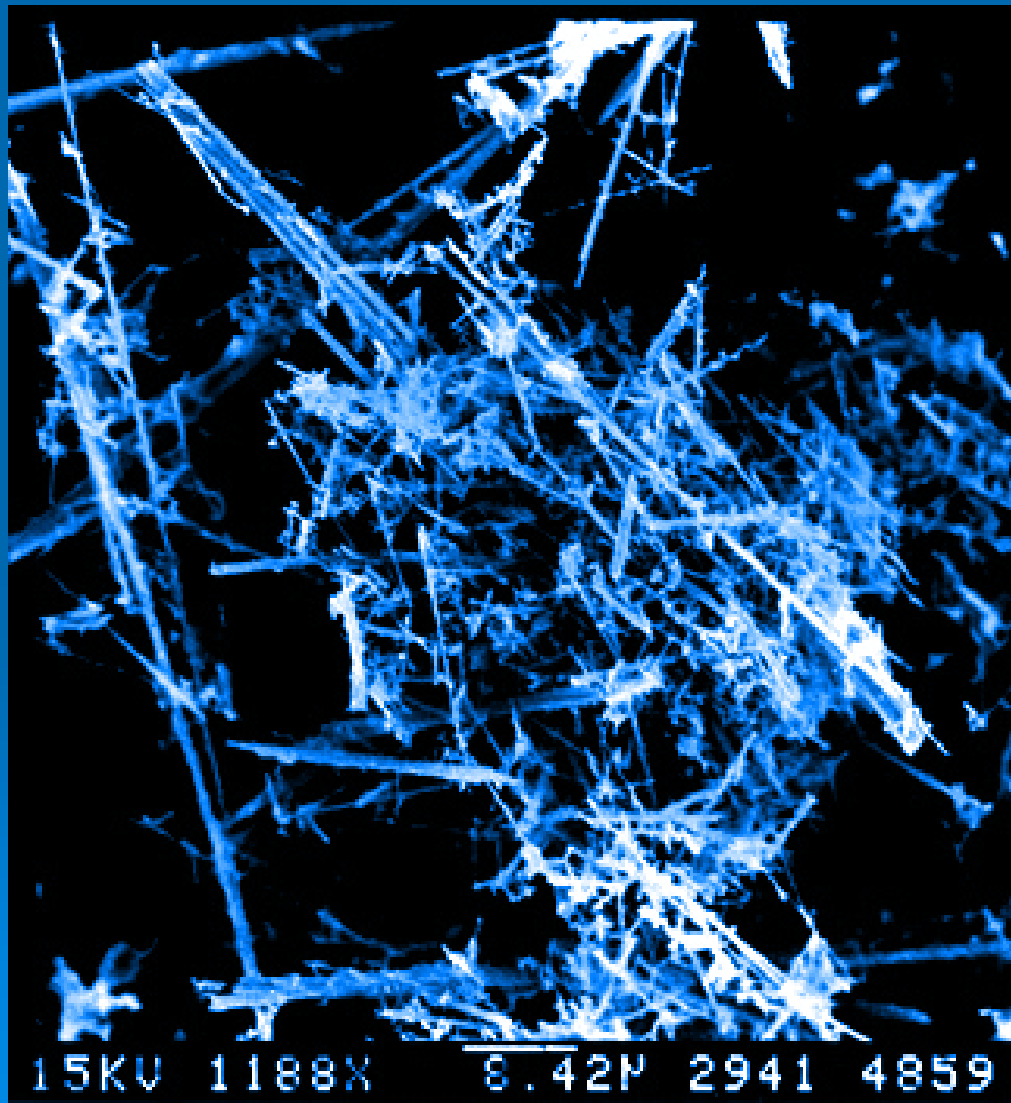
- Ø Definition of mesothelioma
- Ø Asbestos in industry
- Ø The study design
- Ø Findings – patients, family carers, healthcare professionals
- Ø Summary of study
- Ø Impact of the study – professional and personal

Definition

Mesothelioma is an aggressive fatal malignant disease of the mesothelial membranes; it usually affects the pleura (92%) but it may also originate in the peritoneum (8%) or, rarely, the tunica vaginalis of the testis (HSE 2005).

It is caused by exposure to asbestos that occurs mainly in the workplace, although para-occupational and environmental exposures are responsible for a small proportion of cases. Most patients die within 18 months; median survival in UK studies is between 8 and 14 months (British Thoracic Society Standards of Care Committee, 2001; Edwards *et al*, 2000).

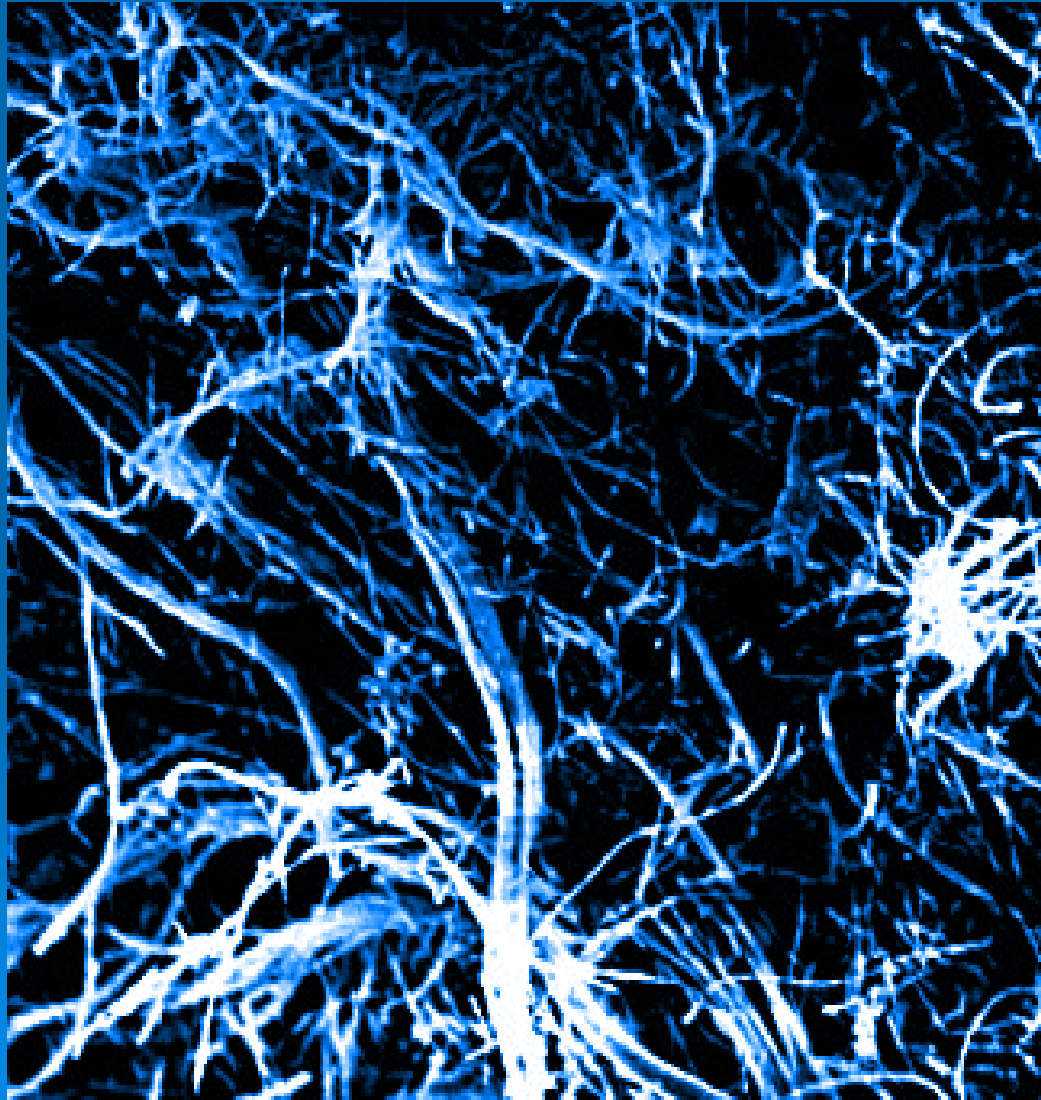
Crocidolite – blue asbestos



Amosite – brown asbestos



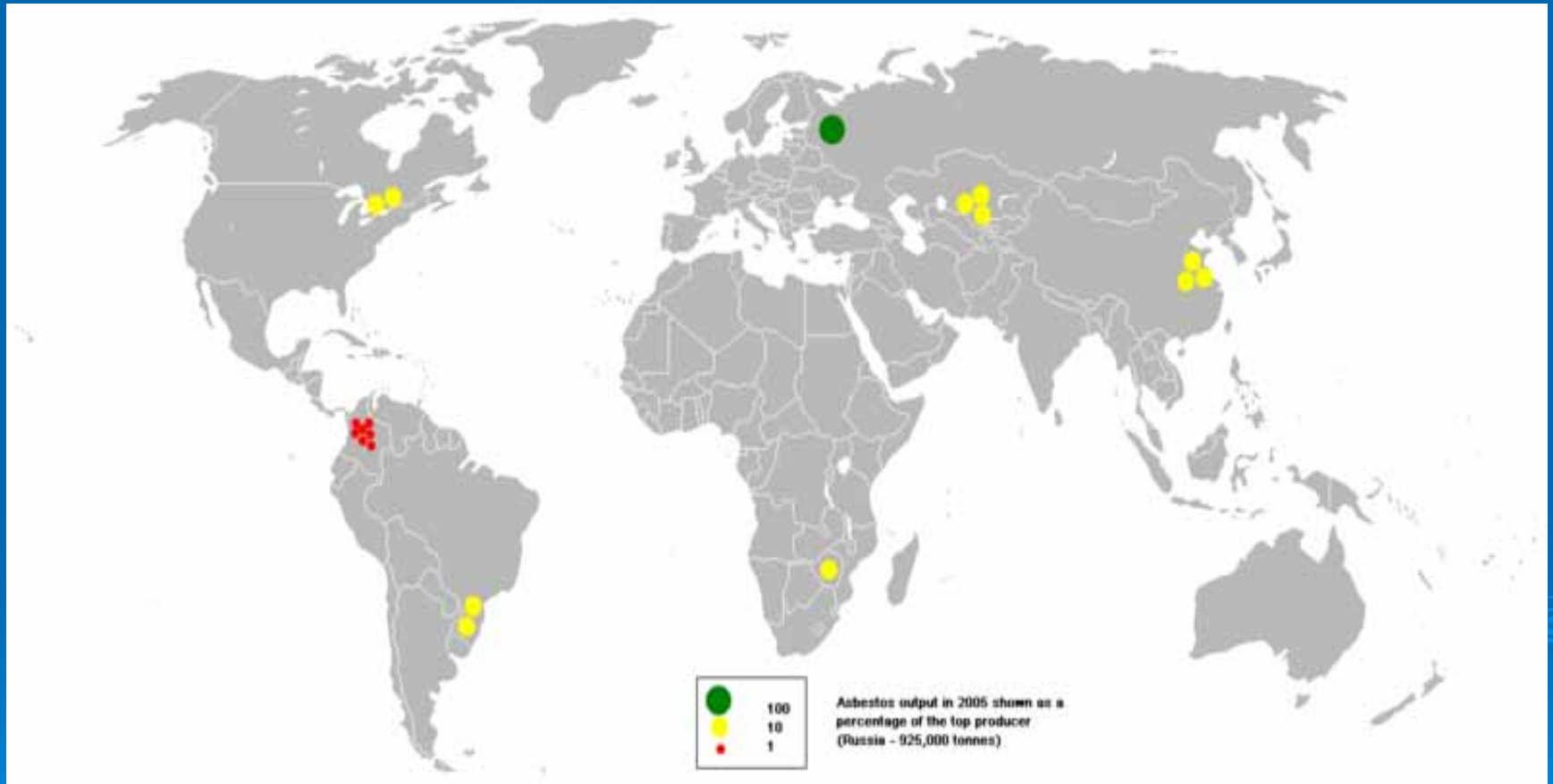
Chrysotile – white asbestos



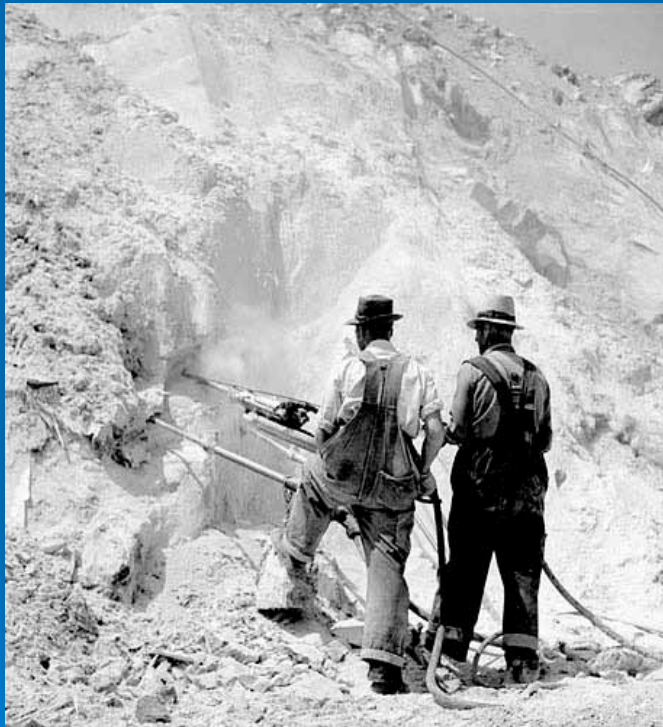
History of asbestos

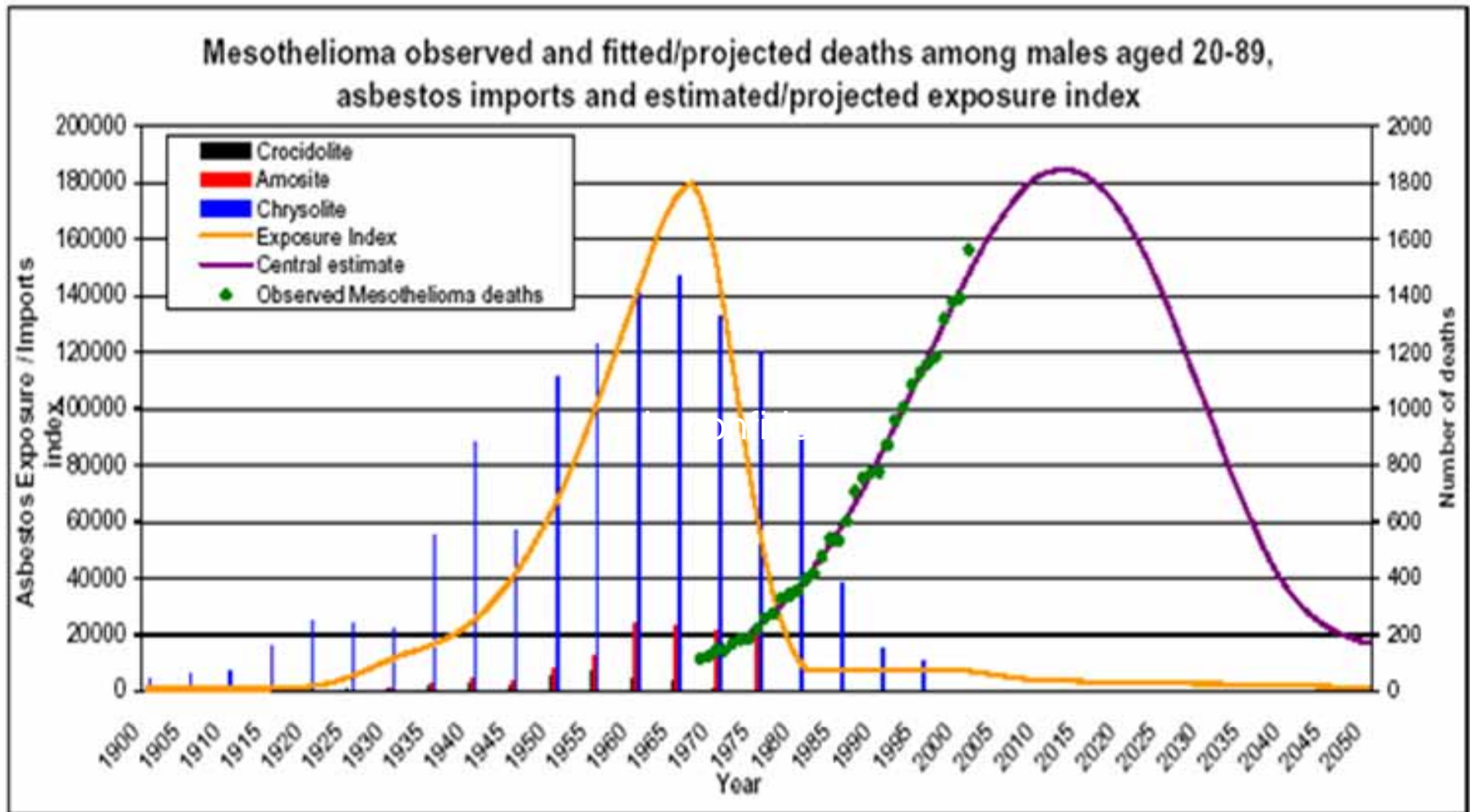
- Ø Pliny the Elder (23-79 AD) noted that slaves working in the asbestos mines died at an early age
- Ø Charlemagne's tablecloth- 'party piece'
- Ø The 'magic mineral' – indestructible insulator
- Ø First record of probable mesothelioma 1870s
- Ø Asbestos associated with mesothelioma 1935 (Gloyne, UK) then 1960 (Wagner, SA)
- Ø UK legal ban on blue and brown asbestos imports 1986
- Ø UK banned white asbestos imports in 1999.

Asbestos production



Asbestos drilling and weaving





Asbestos imports and predicted mesothelioma deaths in the UK (Source: HSE, 2003)

Barrow-in-Furness shipyard 1950s



Barrow-in-Furness shipyard now



'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

The case study approach

- ∅ Multiple sources of evidence
- ∅ Quantitative and qualitative methods used

Initial question 'What are the palliative care needs of mesothelioma?'

evolved into a study of the overarching case: 'The experience of pleural mesothelioma in Northern England'.

Barrow, Leeds and Doncaster = 3 different sites associated with different asbestos-using industries.

The design of the case study

Sub-sets	Units of analysis	Research method
A number of medical records of patients who died with mesothelioma in the 3 sites	Hospital, GP and hospice records of 80 patients who died with mesothelioma	Documentary survey
Patients with mesothelioma in 3 sites with a high incidence of mesothelioma	15 individual patients	15 Semi-structured interviews
A group of bereaved relatives who had cared for a patient with mesothelioma across the 3 sites	6 focus groups of bereaved relatives	Focus groups, 2 in each of the 3 sites
Healthcare professionals involved in mesothelioma care in the 3 sites	11 individual health professionals	11 Semi-structured interviews


Data sources

- ∅ 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)

Occupations of patients interviewed

Asbestos-related occupation	Number of patients
Shipbuilding/engineering	28 (35%)
Railway carriage maintenance and construction	17 (21%)
Buildings maintenance/construction	10 (12.5%)
Power station	5 (6%)
Asbestos insulation & trades	3 (5%)
Stainless steel/copper industry	2 (3%)
Notes recording occupation	65 (81%)
Non-occupational exposure	Number of patients
Family contact/bystander	6 (7.5%)
Environmental	5 (6%)

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. Benefits and civil compensation claims
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Recorded symptoms in mesothelioma

Dyspnoea	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%

Pleural effusions – in 78% cases



Dyspnoea and anxiety

- ∅ *'Fighting for breath', gasping for air', 'drowning in fluid', 'suffocating to death'.*
- ∅ *'I know how bad my father got so I'm expecting the same'*
- ∅ *No sense of 'mastery'*
- ∅ *Terrifying to witness*

Palliation of breathlessness

- Ø Breathlessness is worse in mesothelioma than in lung cancer (Nowak et al, 2005)
- Ø A variety of approaches may be necessary (British Thoracic Society, 2001)
- Ø Self-help techniques for breathing control **not** recorded in any of the 80 records and not mentioned by any of the 15 patients interviewed

Pleural aspiration

Not always a straightforward procedure:

'It was a terrible ordeal. No pain, no. Not painful at all, but it's the weirdest experience.I practically was in shock...And he'd only took about 500mls out and it just so happened that the consultant walked in while the lad was doing it and I was going 'Oh, oh God, I feel as though I'm dying.' I was going to pass out, you know. I was going hot and cold and the sweat was pouring off and he (the consultant) walked in and said 'You'd better stop now. He said 'Can't you see that he's close to going into shock?

Mr CI, 50yrs, ex-shipyard apprentice

Pleurodesis

From the medical records review:

	Barrow	Leeds	Doncaster
Pleural aspirations in last 12/12	102	33	37
Pleurodesis performed	8	16	11
Thoracic surgery referral	4	12	9
Success rate	30%	83%	62%

Invasive investigations and interventions



Pain in mesothelioma

Mr Y: '...good grief, violent pains...I had another day off, and that went away. Then a fortnight after that...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

Mr A: '... 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.'

Retired shop manager

Palliation of pain

- ∅ Pain scores are higher in mesothelioma than in lung cancer (Nowak 2005)
- ∅ Early involvement of a pain specialist is often needed (British Thoracic Society, 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, 2006)

A high disease burden

- ∅ Multiple investigations and invasive procedures
- ∅ 3 times as long to diagnosis as in lung cancer – median **79** days
- ∅ 2 or 3 hospital admissions in final year
- ∅ 5 clinic appointments “
- ∅ 11 GP consultations, 4 of these at home
- ∅ Poor prognosis

Thorpe power station



Finding out about mesothelioma

- ∅ Referral from GP rarely delayed
- ∅ Diagnosis often delayed (79 days median time to diagnosis)
- ∅ 'Damocles syndrome'
- ∅ Consultant usually disclosed diagnosis
- ∅ Majority told 'no cure'
- ∅ Advised to claim at time of disclosure of diagnosis

Hearing the diagnosis

- ∅ *'My mind just went blank....'*
- ∅ *'He said "There's nothing they can do"'*
- ∅ *' We were in total shock...we just wanted to get out of there and go home'*


Reactions to the diagnosis

- ∅ Shock then resigned acceptance but I man 'devastated'
- ∅ Asbestos causation accepted by patients but some queried the route
- ∅ *'The nurse says to me "Are you all right?" I says "No I am not all right!" I thought "You've just told me my husband's going to die....Am I all right?" ...I can remember the saucer and cup clanking, and my husband was so calm, I thought "How can he be like this and I'm like this?" And he drove home, how he did it I don't know. Looking back he said "How did I do that?"' (Gillian, fg4)*
- ∅ Stoical accounts from patients contrasted with highly emotional accounts from bereaved relatives

Bad news broken badly

- ∅ *'..and my husband said to him "How long have I got?" and he said "Well, how long is a piece of string?" We were given no...' (Grace, fg3)*
- ∅ *'Sorry, but those were the words he used to me: "How long is a piece of string?"' (Janet, fg3)*
- ∅ *'...and there was like 6 people sat there in the room when I walked in. The first words he says to me "Have you made a will?" I said "Pardon?"' the consultant repeated his advice to make a will and told her that Bob had only got 2 weeks to live 'then he said "Any questions?" And Bob and I looked at each other and, well, under the circumstances, I don't think there was anything we could say' (Dora, fg1)*

Psychosocial distress

- ∅ Adjustment to facing death
 - ∅ Anxiety before & throughout the illness
 - ∅ Body image issues *'this isn't me...'*
 - ∅ Contamination of family members
 - ∅ Claims and benefits procedures
 - ∅ Attribution issues
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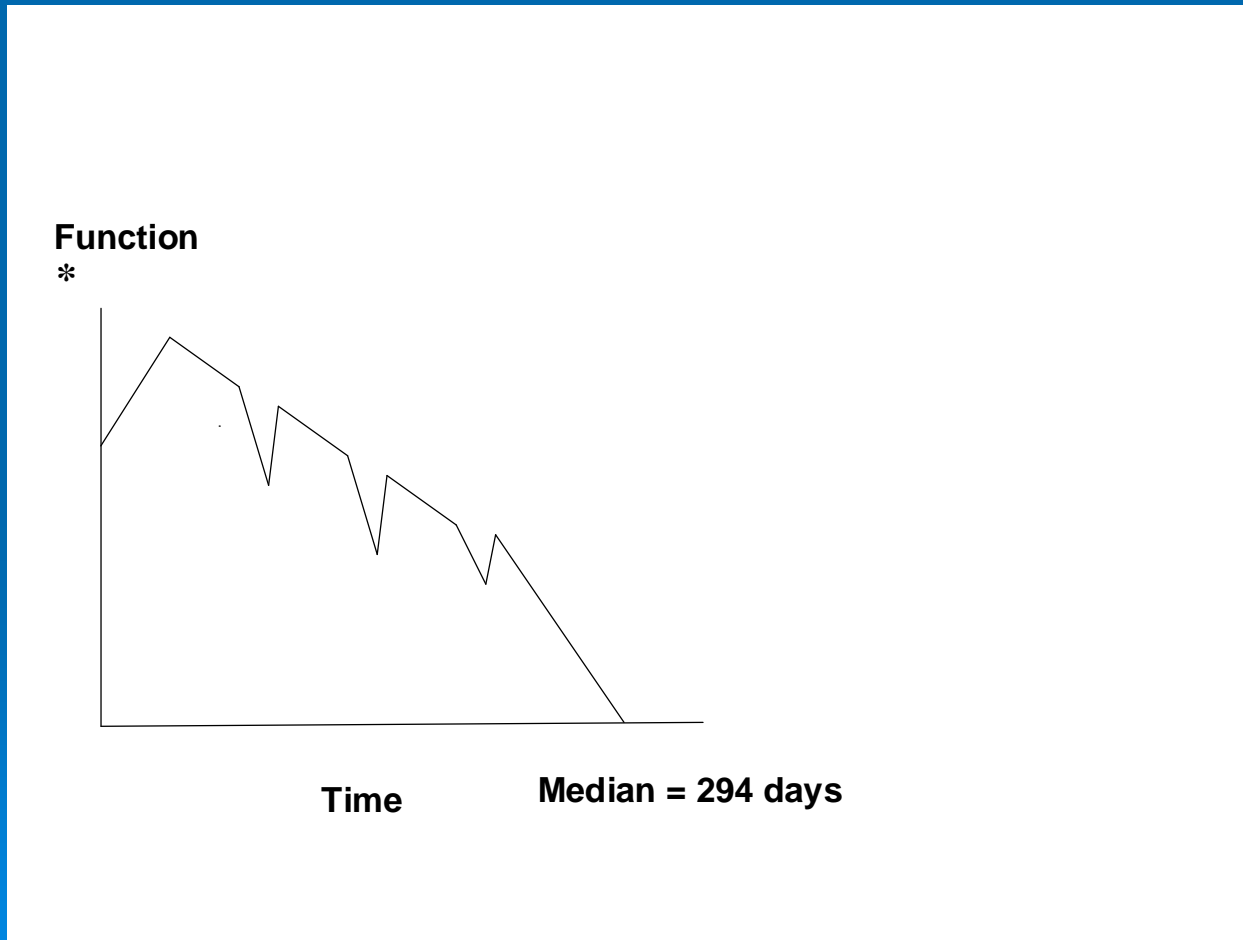
The 'coping narrative'

- ∅ 'We're coping'
- ∅ 'Coping' in spite of significant symptoms and distress – a 'restitution narrative'
(Frank 1995. The wounded storyteller: body, illness and ethics. University of Chicago Press.)
- ∅ The 'coping narrative' is an important strategy: restores a sense of control, bolsters self-esteem and inhibits enquiry/disclosure
- ∅ BUT it may block useful interventions

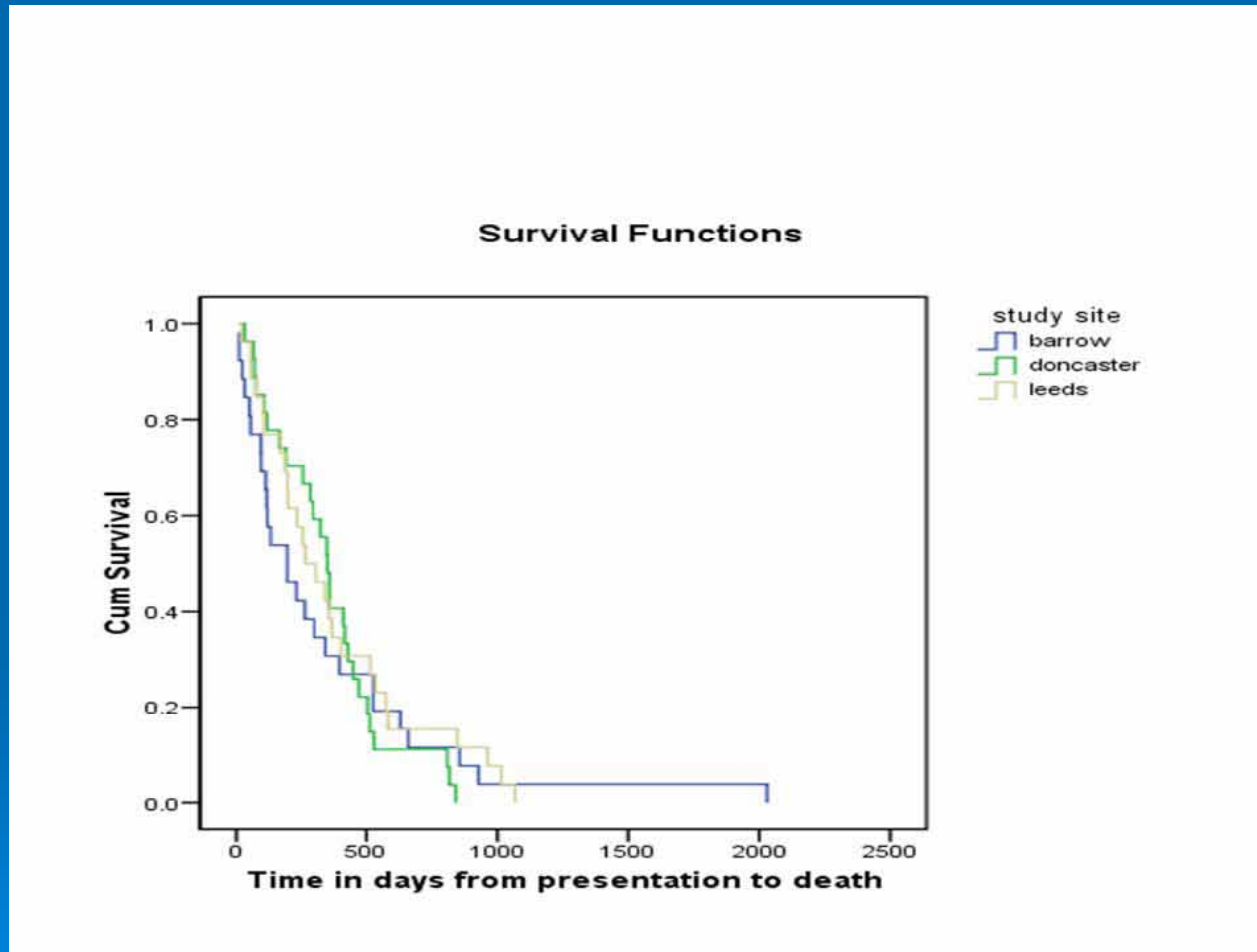
Coping with terminal illness

- ∅ Determined to cope
- ∅ Stoicism/fatalism
- ∅ Only one expressed anger
- ∅ Attempting to stay healthy
- ∅ 'Putting on a false front'
- ∅ Practical plans
- ∅ 'In it together'

An unusual disease trajectory in cancer

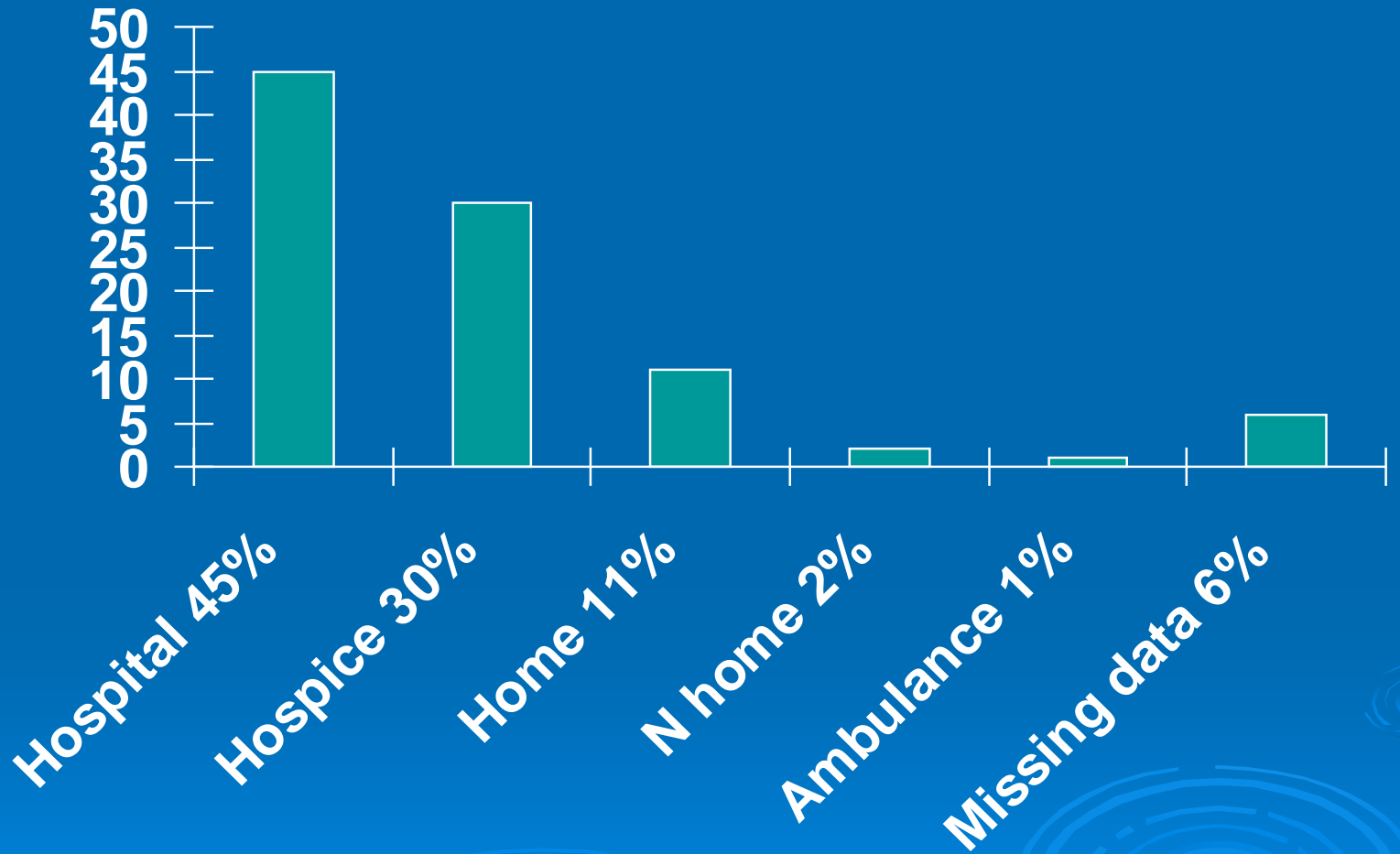


Kaplan-Meier survival curves by location

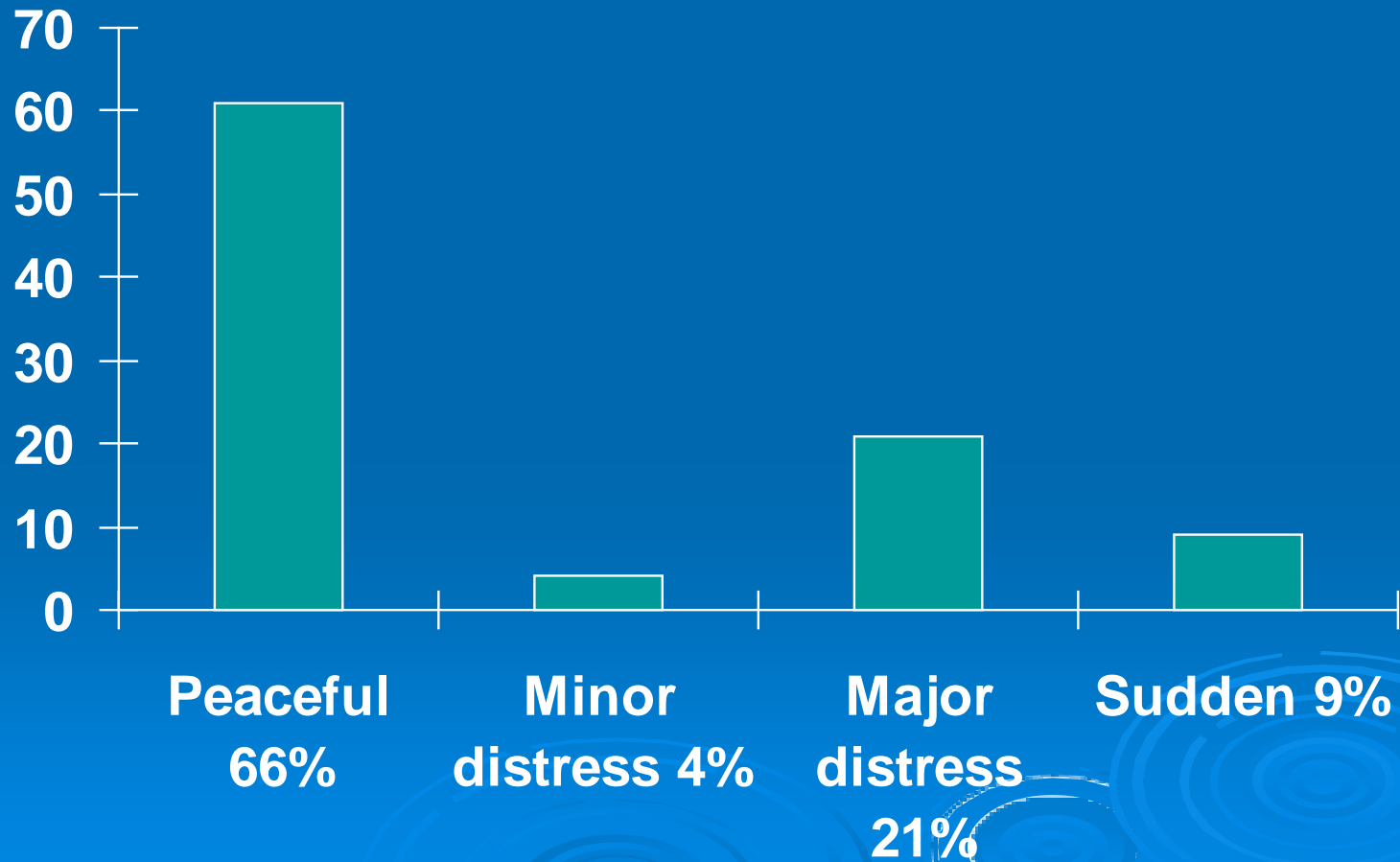


Median survival 294 days from presentation, 63% died within 12/12

Place of death



Mode of death (n=52)



Distressing deaths

- Ø *'...they have the whole thing about the choking, and that's what it is, they're just sort of drowning in the fluid, and it's very distressing when you see it.'* (Don sobbed as he recalled the way in which his father had died, fg2)
- Ø *'...and he felt he was being pushed under water and he just couldn't breathe.'* (Grace, fg3, clearly upset at this painful memory)
- Ø *'I was there by myself and this vile black substance came out of his mouth...It kept coming every time he coughed...he said to me: 'You wouldn't let a dog suffer like this.' At the end of 36 hours the staff said 'We really are going to have to sedate him now' and they told me to say what I needed to say to him. Again – the opposite effect – he was thrashing about, trying to raise himself in the bed, eyes out on stalks, terrified, pouring out stuff from his earlier years all jumbled up together like he was on drugs...and all the time this vile black stuff was coming out of his mouth...he had no relief. The nurses asked us to leave the room so they could use the suction, then we heard a most terrible noise and they said to come back in quickly. His eyes were out on stalks, he was terrified and we could only hold his hands and try to comfort him as he died.'* (Sue, fg6)

Carers' issues

- Ø Caught up in the 'coping narrative' & put patients' needs first
- Ø Erratic dramatic trajectory is demanding and causes severe anxiety
- Ø Specific needs for information in order to anticipate and plan (but little time for anticipatory grieving)
- Ø Often have other caring responsibilities
- Ø Legal procedures after death - very distressing and prevent 'closure'.

Carers' issues

- ∅ Adopt the 'coping narrative': put patients' needs first **but** in bereavement tell a different story
- ∅ Unpredictable dramatic trajectory and lack of accurate information >severe anxiety
- ∅ Need for information in order to anticipate and plan

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

- Ø Outrage and persisting distress – *'avoidable deaths'*, *'avoidable suffering'*
- Ø Legal procedures after death (in UK) are very distressing and prevent 'closure'.
- Ø 'Tragic grief' common

‘An inquest? I’ve done nothing wrong’



'...this is a depressing disease...' **(Thoracic surgeon)**

- Ø Emotionally demanding
- Ø Doctors felt hopeless, sad and impotent, sometimes angry
- Ø Nurses shared the distress of patients and families
- Ø All felt dissatisfied with aspects of the services available to patients
- Ø Anger expressed by relatives was understood by professionals but added to the emotional toll
- Ø The psychosocial burden of mesothelioma is difficult to ignore due to lack of effective treatments and burden of compensation processes

Workload due to mesothelioma

GP	1-2/year
Respiratory physician	4-6 new patients/year
Macmillan nurse	Up to 10 patients/year
Oncologist	Up to 15/year
Thoracic surgeon	2-3 patients/week (some 'repeats')
Help-line nurse	Around 1000 calls/year
Respiratory ward sister	Decreasing since new admissions policy

A unique situation

'...I can't think of many other sorts of cancer where at least nothing is offered, where no cure is offered, there's no hope offered to you.'
(GP)

'Now I'm aware that we got the most difficult, the complicated, the failures if you like, in the system, but... managing these patients was more difficult because of them having a delay in their diagnostic phase...contractions and the distortion of the chest wall, which you don't tend to get with lung cancer. I think pain is more of a problem generally than with the average lung cancer because it's a pleuritic disease rather than a lung disease really.'
(Palliative medicine consultant)

Professionals' views re chemotherapy

- ∅ All healthcare professionals regarded chemotherapy as palliative
- ∅ Mixed views re trials: in general, hospital doctors favoured recruitment into trials, community healthcare professionals more hesitant or opposed
? utilitarian versus individual outcomes
- ∅ Awareness of ethical issues around futile treatments, autonomy, opportunity costs and treatment burden
- ∅ Awareness that patients may be more accepting of burden of treatment than doctors and also that decisions are influenced by professionals

Palliation of symptoms

- Ø Under-prescribing and inappropriate prescribing perceived to be common outside palliative care
- Ø Specialist palliative care needed but differing views about when to involve
- Ø Control of pain and dyspnoea felt to be particularly difficult
- Ø Dyspnoea seen as mainly due to effusions: regarded as treatable by doctors, nurses reported inefficient and sometimes inadequate management

Doctors feelings about talking to patients about mesothelioma

- Ø Particularly difficult bad news – ‘shared hopelessness’
- Ø Agreed role of specialist nurse is to expand on diagnosis and management but some nurses felt compromised by lack of knowledge, selective/limited information given by doctor particularly re clinical trials, risk of contradiction, no guidance re best practice
- Ø Nurses took responsibility for providing information booklets, access to support groups & benefits advisors

State benefits and civil compensation

- Ø Doctors were keen to mention compensation at disclosure of diagnosis, nurses disagreed
- Ø No systematic approach or guidance as to best time although financial entitlements very important for some families
- Ø Nurses aware they should not advise on medico-legal issues but do need to understand the processes
- Ø Nurses reported assisting patients to complete benefits claim forms


Summary of findings

- ∅ Patients and their families are faced with a particularly difficult set of circumstances
- ∅ A devastating disease that carries a severe burden in physical, psychological and social domains
- ∅ Breathlessness and/or pain affect >90% patients and may be refractory
- ∅ Psychosocial aspects relate to causation, latency, rapid decline in health, helplessness regarding severe symptoms, and impending death alongside the demanding procedures for claiming State benefits and civil compensation – anxiety is severe.

Overview

- The combination of a severe disease burden with additional distress due to benefit and compensation claims causes extreme suffering
- Stoical accounts from patients contrast dramatically with bereaved relatives' accounts
- Medical nihilism and doctors' and nurses' distress were evident
- Patients and family members were distracted and distressed by complex medico-legal issues

Implications

- ∅ Palliative care should be involved early and systematically
 - ∅ Palliative care should be seen as a positive option
 - ∅ Palliative care should run in parallel with any active interventions
- 

Personal impact

- Ø Novice researcher
- Ø A demanding study
- Ø Time to plan and to recruit
- Ø Generated large amounts of qualitative data
- Ø Managing Atlas-ti software
- Ø Deciding which information to leave out
- Ø Time to write up
- Ø Emotional impact
- Ø Impact on a small practice
- Ø Precipitated major personal and career changes

But - it prevented burn out and introduced me to many new fields of interest and some wonderful people.

Professional impact

Dissemination:

- ∅ International conferences x 14
- ∅ Presentations – medical, occupational health, HSE, political eg APPG asbestos subcommittee, UCATT, European School of Oncology, asbestos support groups.
- ∅ Media interviews
- ∅ Contributed to UK, European and Egyptian guidelines on mesothelioma/management of malignant pleural effusions
- ∅ Publications – 3 papers, co-author 1 book chapter (3 papers pending)
- ∅ www.mesothelioma.uk.com symptom control section

Other activities:

- ∅ Set up support group: BARDS
- ∅ Organised 2 BARDS national conferences
- ∅ NCARD steering group for palliative care
- ∅ Member of RCGP expert resource group for respiratory conditions
- ∅ Book reviews
- ∅ Numerous enquiries from patients/family members and professionals
- ∅ Has left me with a wish to do more.....

BARDS: Barrow Asbestos-Related Disease Support

- ∅ A unique 'one stop shop' service -meeting one half-day a month in Barrow; collaboration between hospice, unions, CAB, Benefits service, legal firms. Mandate from Participatory Appraisal conducted in Barrow in 2005.
- ∅ All asbestos diseases included
- ∅ Doctor, lawyer (rota of 8 firms), benefits advisor, volunteers & now the BARDS mesothelioma nurse
- ∅ Referral to complementary therapies, breathing control sessions, physiotherapy, dietician, psychologist, carer support services, bereavement service etc
- ∅ 24/7 telephone advice via HospiceLine



'Lady Asbestos' by Bernard Partridge taken from an advertisement for asbestos products ~1918
(Reproduced with permission of Tommy Gorman (2000) (ed) *Clydebank: Asbestos the unwanted legacy*).

Acknowledgements

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