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# The Experience of Mesothelioma in Northern England

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degree of MD

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# Thesis summary

Mesothelioma is a potentially preventable fatal disease causing almost 2000 deaths/year in the UK, increasing in incidence, and lacking effective treatments. 'The Experience of Mesothelioma in Northern England' is a community-based, mixed methods, case study in four parts, conducted in Barrow-in-Furness, Leeds and Doncaster. The study investigates the experience of pleural mesothelioma for patients and their families, and for healthcare professionals and service providers.

Mesothelioma is experienced as a devastating disease that carries a severe burden in physical, psychological, and social domains. Breathlessness, usually due to recurrent pleural effusions, and/or pain occur in >90% cases and may be refractory. Psychosocial aspects relate to causation, latency, rapid decline in health, helplessness regarding severe symptoms, and impending death. The erratic trajectory is unusual in malignancy. Disease burden is high in terms of multiple invasive investigations and emergency admissions and is reflected in service usage: 2 or 3 hospital admissions, 5 outpatient appointments and 11 GP consultations, 4 of these at home, occurred on average in the last year of life. Median survival was 294 days and 45% died in hospital, 30% in hospice, and 14% at home. Patients tend to react with stoicism and patients (and relatives) adopt a 'coping narrative' which may prevent timely access to supportive services. Bereaved relatives' emotional accounts reflect witnessing severe suffering, express anger and blame around the potentially avoidable asbestos exposure, and present the deaths due to mesothelioma as 'mass murder'. State benefits and civil compensation procedures, and the Coroner's investigation, create additional distress. Severe bereavement reactions have features of 'tragic grief'. In spite of the severe symptom burden, less than half of the patients were referred to palliative care and there was no systematic approach to care and support of either patients or their relatives. The study has implications for research and service provision.

# Acknowledgements

This work would not have been possible without the unstinting support of my two academic supervisors, Dr Bill Noble and Professor Jane Seymour. Generous with their time, always offering constructive criticism, and unfailingly encouraging, their contribution has been considerable and I will always be grateful for their help and friendship. I am also grateful to Dr Peter Bath who provided invaluable advice and support concerning the collection, handling and analysis of quantitative data. I feel that I have been accompanied and nurtured through a period of deeply satisfying personal and professional development.

I also wish to thank my husband, family and friends for their tolerance and assistance during the study; I have been distracted from normal family and social life as much of the work has been done in my 'spare' time. Similarly, I wish to thank colleagues, the Trustees, and the Bursar, at the Hospice of St Mary of Furness, who encouraged me whilst conducting this study, particularly as it relates to a disease that has local relevance and a significant impact on the hospice. In addition I am very grateful for funding from the Scientific Foundation Board of the Royal College of General Practitioners.

Finally, my thanks are due to the patients, relatives and healthcare professionals who contributed to this study. It is my hope that the completed study fulfils their expectations in helping those who are affected by mesothelioma in the future.

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# Chapter 1: Introduction

## 1.1 Mesothelioma

### *Definition of mesothelioma*

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 (Health and Safety Executive, (HSE), 2005a). 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 (BTS) Standards of Care Committee, 2001; Edwards *et al*, 2000).

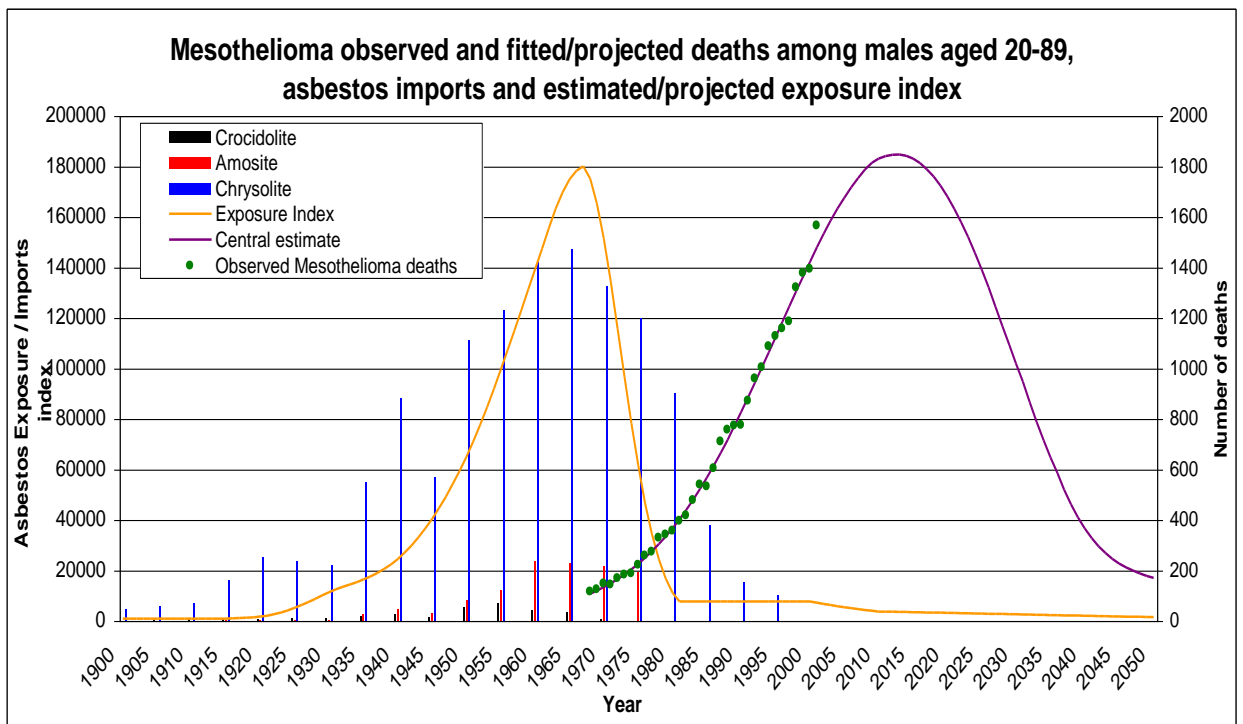
### *Epidemiology*

Mesothelioma has been described in the medical literature since 1870 but was possibly described earlier in a French paper in 1767. Gloyne (1935) published the first UK report suggesting a causal link between asbestos exposure and mesothelioma (McDonald and McDonald, 1996). However it was an influential paper by Wagner *et al*, (1960), confirming a strong link between exposure to crocidolite asbestos and pleural mesothelioma, that finally convinced the medical establishment of the connection and demolished the persistent denial of asbestos-related disease by the asbestos industry (Tweedale, 2000: 53).

People in high-risk occupations for mesothelioma are metal plate workers (including shipyard workers), vehicle body builders (including railway carriage builders), plumbers, gas fitters, joiners and electricians. Industries with the highest incidence are construction and extraction (including insulation and asbestos removal), energy, and water supply. The traditional UK shipbuilding areas, West Dunbartonshire and Barrow-in-Furness, have the highest incidences of mesothelioma with standardised mortality rates (SMR) for men of 637 and 593 respectively (HSE, 2005b).

Heavy exposure to asbestos in these settings has slowly become a thing of the past in the developed world due to health and safety legislation and, more recently, a complete ban on use of all types of asbestos and its importation in most European countries. In the UK, amosite and crocidolite were banned in 1985, and chrysotile was banned in 1999 (Tweedale, 2000: 2). The World Trade Organisation, which primarily exists to protect free trade, has supported the European Union asbestos import ban (Kazan-Allan, 2002).

A Mesothelioma Register, based on death certificate data, was introduced in the UK in 1967 and figures have shown a steady increase since then with 1969 deaths recorded in 2004 (HSE, 2006a). As the maximum use of asbestos in the UK occurred in the 1960s and '70s, and because mesothelioma exhibits a latency of 15 to 60 years from exposure to disease presentation, epidemiologists predict a rising incidence of mesothelioma in Europe, to peak around 2015 (Figure 1.1)



**Figure 1.1: Asbestos imports and predicted mesothelioma deaths in the UK (Source: HSE, 2003)**

Mesothelioma may then account for the deaths of up to 1% of British men born in the 1940s, at around 1950 to 2450 per annum (Hodgson *et al*, 2005). However reports from the UK and US suggest that this may be underestimated by up to 20% because the predictions are based on death certificate data; estimates arising from cancer registry data are considerably higher (Pinheiro *et al*, 2004). Now that exposure to asbestos in heavy engineering and construction industries has declined in Europe, mesothelioma will increasingly occur in people who are exposed to *existing* asbestos in the fabric of buildings in the course of their work, for example as buildings maintenance tradesmen and demolition workers, or possibly as 'do-it-yourself' enthusiasts. This shifts the location of cases away from clusters around the shipyards, railway plant works and asbestos factories, to a more generalised distribution (McElvenny *et al*, 2005). Disturbingly, a recent Swedish study involving construction workers suggests that, rather than the expected reduction in incidence of mesothelioma due to their banning of asbestos 25 years ago, there may actually be an increase (Engholm and Englund, 2005). The situation in poorly-resourced countries is disturbing: in India in 2001 more than 30 asbestos mines were operating and employing around 100,000 workers (Ramanathan and Subramanian, 2001).

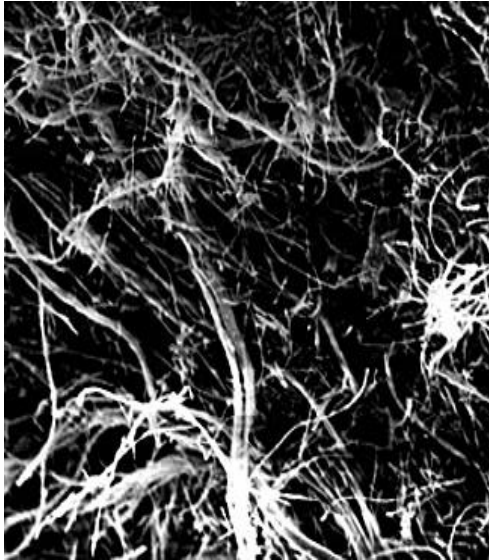
Para-occupational exposure can result from close contact with asbestos workers, for example, wives of asbestos workers have developed mesothelioma due to inhalation of asbestos dust when laundering their husbands' overalls (Howel *et al*, 1997). Significant environmental exposure occurs in the vicinity of asbestos mines and manufacturing factories (Wagner *et al*, 1960; Hillerdal, 1999) and also from deteriorating asbestos materials in commercial and domestic premises. This latter source probably accounts for the fact that currently one in four UK patients with mesothelioma has worked in the building or maintenance industry (HSE, 2006b). The World Trade Centre disaster on 9.11.2001 released considerable quantities of asbestos and resulted in contamination of rescue workers, local residents and workers, surrounding homes and offices, (Chatfield, 2001). The devastation caused by Hurricane Katrina includes asbestos contamination amongst more immediately dangerous chemical pollutants (U.S. Environmental Protection Agency, 2006). Asbestos

contamination in storage of some sensitive UK government documents has been cited as the reason for not making them available to the public, (House of Commons Hansard, 2004), a situation in conflict with the introduction of the Freedom of Information Act, (2005).

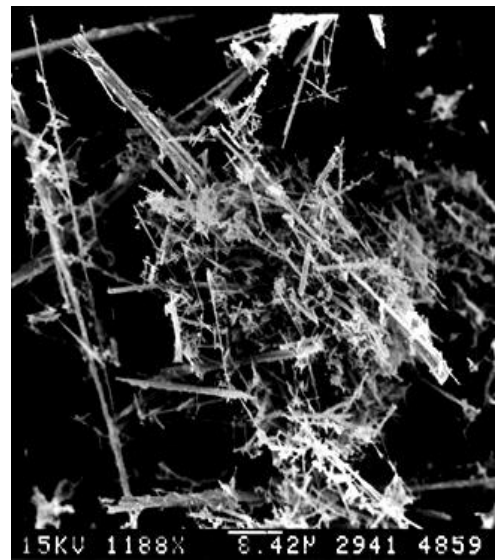
Mesothelioma occurs in animals, affecting dogs and cattle most commonly. Peritoneal disease occurs more frequently than pleural mesothelioma, presumably due to ingestion rather than inhalation of asbestos materials. Intriguingly, calves appear to develop congenital mesothelioma (Armed Forces Institute of Pathology, 2000).

### *The role of asbestos*

Asbestos encompasses a group of around 6 naturally occurring fibrous silicates widely distributed in nature. Its name derives from the Greek meaning 'inextinguishable' or 'unquenchable', demonstrating that its physical properties were known in ancient times: wicks for Greek temple lamps were said to have been made from asbestos and Pliny the Elder believed that asbestos resisted all magic potions (Selikoff and Lee, 1978; Pliny the Elder, 1991:360). Asbestos occurs in two main forms: the serpentine type, known as chrysotile or 'white' asbestos that has long wavy fibres, and the needle-like amphibole types including crocidolite known as 'blue' asbestos and amosite or 'brown' asbestos, (Figure 1.2). The name amosite was derived from Asbestos Mines of South Africa (Tweedale, 2000:2). Crocidolite occurs as 'blue clay' in Da-yao county, China, where, until recently prohibited, villagers used it to make asbestos stoves for heating and cooking, it was also used as colourful stucco for home decoration. Pleural plaques are present on X-ray in 20% of Da-yao villagers aged over 40 years and 22% of cancer deaths in the locality are due to mesothelioma (Luo *et al*, 2003). Erionite is a zeolite, an asbestos-like mineral that occurs naturally in eastern Turkey and where it is widely used as a building material. In this region, mesothelioma accounts for over 50% of deaths (Emri *et al*, 1979).



**Chrysotile**



**Crocidolite**

**Figure 1.2: Electron microscope slides of asbestos fibres**

Asbestos fibres are extremely resistant to heat and almost indestructible by physical force, crocidolite is also resistant to acids. Crushed asbestos rock forms soft fine filaments that can be spun into lightweight strong fibres. These had over 3000 industrial and domestic uses: as woven textiles, added to cement, in insulation and friction materials, wall and floor boards; asbestos was also used in filters for gas masks and cigarettes (Levin *et al*, 2000).

In the 19<sup>th</sup> century, when the industrialisation of Europe and America was dependent on steam driven machinery, the high temperatures generated by these engines posed a major practical problem. The need for insulating materials led to the development of the asbestos industry from 1890 onwards; mining of asbestos escalated in Canada, South Africa and Russia. Turner, an industrialist, initiated large-scale production of asbestos insulation materials in the UK at the turn of the 19<sup>th</sup> century. Subsequently his family firm merged with Newalls, the largest insulation business, and three other major asbestos companies in Britain, to form Turner and Newalls which eventually held 20% of the world asbestos market and was in the top 100 UK firms (Tweedale, 2000:9).

The success of asbestos fireproofing and insulation in industry and shipping earned its early nickname 'the magic mineral' and the positive image of 'Lady Asbestos', (Figure 1.3), (Gorman, 2000:130). Asbestos insulation in warships

was credited with saving many British lives, for example, in the Battle of Jutland in 1916. Ironically, the removal of asbestos from British Navy ships in compliance with the Asbestos Regulations of 1969, in order to reduce asbestos hazards to servicemen, was cited as the reason for heavy loss of life from fire on ships during the Falklands War in 1982 (Newman-Taylor, 2002). Heavy industry used large quantities of asbestos in Europe during and after World War II; the UK imported more crocidolite and amosite per head from South Africa between 1945 and 1963 than any other country (May, 1965). Russia is the world's largest producer of asbestos but virtually all is used domestically. Canada is the second largest producer, and the world's largest exporter of asbestos as there is virtually no domestic market, (Kazan-Allen, 2002).



**Figure 1.3: '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*).**



## *Industrial Disease*

Mesothelioma is a UK Prescribed Disease, one of the four asbestos-related diseases that are recognised for the purposes of a specific State benefit, Industrial Injuries Disablement Benefit (Box 1.1). Claims may also be made against the responsible employers for civil compensation. These issues are described in more detail in section 1.6: *Mesothelioma, the law and society*. Mesothelioma is the most common cause of death due to industrial malignancy in the UK (HSE, 2006a).

**Box 1.1: Prescribed asbestos-related diseases and ‘particular’ occupations**  
(National Insurance Regulations, 1966)

D1: Pneumoconiosis (asbestosis);

D3: Diffuse mesothelioma (primary neoplasm of the mesothelium of the pleura or of the pericardium or of the peritoneum);

D8: Primary carcinoma of the lung where there is accompanying evidence of one or both of the following (a) asbestosis, (b) bilateral diffuse pleural thickening;

D9: Bilateral diffuse pleural thickening

The occupations for which these conditions are prescribed:

- (a) working or handling asbestos, or any admixture of asbestos;
- (b) manufacture or repair of asbestos textiles or other articles containing or composed of asbestos;
- (c) cleaning of any machinery or plant used in any of the foregoing operations and of any chambers, fixtures, appliances for the collection of asbestos dust;
- (d) substantial exposure to dust arising from any of the foregoing operations.

## **1.2 Clinico-pathological features**

### *Pathogenesis*

Chronic irritation and inflammation due to asbestos fibres are involved in producing malignant change. A small number of mesothelioma cases, possibly 50 – 100 per year in the UK, may develop independently of asbestos but the aetiology is unclear (HSE, 2006c). Other factors may be involved: genetic susceptibility, direct effect of asbestos on DNA, stimulation of proto-oncogenes

and possibly simian virus 40 (SV40) but their exact roles are unclear (Carbone *et al*, 2002, and 2006; Nowak *et al*, 2002). Mesothelioma is regarded as a dose-dependent disease, even brief heavy asbestos exposure can be lethal (Hillerdal, 1983; Peto *et al*, 1999). Amphiboles demonstrate greater carcinogenicity than chrysotile due to differing biopersistence (Gibbs, 1990). Latency between exposure and disease presentation ranges from 15 to 67 years with a mean of 41 years (Yates *et al*, 1997).

Asbestos fibres migrate to the periphery of the lung and into the pleural space from where lymphatic drainage takes them to the parietal pleura where they become implanted in the early stage. Fibre size is critical: mesothelioma results from fibres of 3µm or more in length and less than 0.1µm in diameter; most commercially-produced fibres are larger than this (Hillerdal, 1983). The deposition of fibres tends to favour the right lung (60%), possibly due to the larger size of the right pleura. Irritation of the pleura accounts for the development of pleural effusions and the tumour then extends into the visceral pleura and around the affected lung. Mesothelial cells produce fibrin and collagen which form a thick 'rind' that frequently extends into the contralateral pleura as well as the pericardium and, via the diaphragm, into the peritoneum (Hillerdal, 1983). Mesothelioma arises in the pleura in 95%, in the peritoneum in 5% (Yates *et al*, 1997).

Smoking and asbestos act synergistically as co-carcinogens in lung cancer. Asbestos exposure increases the risk of lung cancer in non-smokers and smokers by factors of 10 and 100 respectively (Cancer Research UK, 2006; Lee, 2001a); this amounts to around one case of asbestos-related lung cancer for each mesothelioma (HSE, 2006b).

Mesothelial cells are pluri-potential because they derive from ectodermal and endodermal layers, this results in several histological types of mesothelioma including 'mixed' (Donna and Provana, 1977), Table 1.1. Identification of the particular histology can be difficult: the epithelioid type resembles adenocarcinoma and the sarcomatous type may be hard to distinguish from inflammatory reaction in the mesothelium.

<b>Histological type</b>	<b>Percentage</b>
Epithelial	50%
Mixed	34%
Sarcomatous or spindle cell	16%

**Table 1.1. The main histological types of mesothelioma** (Hillerdal, 1983)

### *Prognosis*

Prognosis varies according to histological type: epithelioid tumours give the longest survival, Table 1.2. There is no explanation why particular types develop in individual patients although Hillerdal (1983) proposes that the ‘gross environment of the tumour’ is a factor. Pleural plaques are present in around 29% of cases of mesothelioma and indicate asbestos exposure but are not regarded as pre-malignant (Yates *et al*, 1997). Patients with asbestosis, that is, pulmonary fibrosis due to asbestos, have a 10 – 15% risk of dying from mesothelioma (Hillerdal, 1983).

<b>Source</b>	<b>No of cases</b>	<b>All types</b>	<b>Epithelioid</b>	<b>Sarcomatous</b>	<b>Mixed or biphasic</b>
Hillerdahl, 1983	153	10	11	5	10
Van Gelder et al, 1994	83	8.1	8.4	6.9	6.3
Johnson et al, 1995		9.2			
Yates et al, 1997	248	14	16.2	10.1	14.7
Edwards et al, 2000	142	5.9			

**Table 1.2: Median survival in months according to histological type.**

## *Screening*

Screening is not recommended for mesothelioma because there is no specific test that establishes diagnosis at an early stage, although high-risk individuals may be monitored by annual chest x-rays in some areas (BTS, 2001). However, there is no evidence that this is effective and it may cause harm: by giving false reassurance when early disease is not detected, by raising anxiety levels due to reinforcing the high-risk status, or by leading to unnecessary investigations when x-rays are inconclusive (BTS, 2001). Recent discoveries of tumour markers such as osteopontin and mesothelin have not changed this situation: although tumour sensitive they are not tumour specific and thus do not have a role in screening; they may be useful in assessing treatment responses, particularly with regard to debulking surgical procedures. However there is a view that in high-risk individuals, these or future markers may be useful in surveillance in order to make earlier diagnoses (Peake *et al*, 2006:41).

## *Clinical features*

Around 90% of UK patients give a history of occupational asbestos exposure (Yates *et al*, 1997). Most cases present as males in their 60s and 70s: the ratio of men to women is at least 12:1, although the male preponderance is increasing as fewer women now work in high risk occupations (HSE, 2006c). Metastases, although found in 55% at post mortem, are rarely significant during the illness (Yates *et al*, 1997).

Most patients present with dyspnoea and/or chest pain, (Table 1.3). Pleural effusion is the most common presenting feature although breathlessness may be multi-factorial. The thickened pleura can become rigid and restrict chest wall mobility, hence a 'frozen chest'. Recurrent pleural effusions are common and can be difficult to drain due to loculation and pleural thickening, and the fluid may be heavily bloodstained. Lung invasion may reduce lung capacity and pericardial involvement, effusion or constriction, may further complicate the picture (BTS, 2001). Initially, chest pain is often dull and not localised, or it may be pleuritic and radiate to arm, shoulder, chest wall or abdomen. As the disease advances, pain may be severe and complex with multiple aetiologies due to involvement of pleura, nerves and neighbouring structures (Hillerdal, 1983).

Two studies suggest that pain may be particularly severe in mesothelioma: a study of opioid-responsiveness of various tumours demonstrated that, uniquely in mesothelioma, opioid requirements continue to rise as the illness progressed (Mercadante *et al*, 2000); in the other study, a quality of life evaluation during a chemotherapy trial using the EORTC QLQ-C30 lung cancer symptom assessment tool (Aaronson *et al*, 1987), pain scores in mesothelioma were significantly higher than those in lung cancer (Nowak *et al*, 2004).

Chest x-ray (CXR) or computerised tomography (CT) scan typically demonstrate pleural effusion, pleural thickening and/or lung involvement by tumour. MRI scanning offers no advantage in diagnosing mesothelioma but it is helpful in determining local tumour extension (Peake *et al*, 2006:43-7).

Symptom	Mesothelioma		Lung cancer
	Higgs and Newbury, 1999.	Ruffie <i>et al</i> , 1989.	Krishnasamy and Wilkie, 1999.
Dyspnoea	79%		>80%
Pain	76%		89%
Dyspnoea and/or chest pain		90%	
Pleural effusion		84%	
Fatigue/weakness	71%	3%	73%
Cough	29%	3%	70%
Anorexia	21%	3%	49%
Weight loss		29%	
Nausea	18%		24%
Constipation	18%		29%
Sweats	15%		
Fever		3%	
Confusion	12%		
Chest lump	12%		
Limb oedema	12%		
Asymptomatic		3%	
Dysphagia	<1%		24%
Haemoptysis	<1%		11%
<b>No in study</b>	34	322	209

**Table 1.3: Prevalence of symptoms in mesothelioma and lung cancer**

### *Confirmation of diagnosis*

Histological diagnosis is usually made from pleural biopsy samples or pleural fluid, or occasionally from biopsy of a metastasis. Open pleural biopsy or, more commonly, video-assisted thoracoscopic (VATS) biopsy, achieve the highest diagnostic yield, approaching 100% (Martin-Ucar and Waller, 2006:252). As there is no specific marker for mesothelioma, the histological diagnosis must be established by a battery of staining and immunological tests that include tests specific for other tumours (King *et al*, 2006a). The problem of differentiating between mesothelioma and adenocarcinoma has led to a call for the establishment of a national reference laboratory (Haselton, 2001).

At post mortem the pleural membranes show extreme thickening and fibrosis, at times almost impossible to incise. Macroscopic nodules and deposits are present, the affected mesothelial membranes become adherent to each other and neighbouring structures; one series demonstrated distant metastases in 55%, pleural plaques in 29% and asbestos bodies in 46% (Yates *et al*, 1997).

### *Disease trajectory*

Poor prognostic features include being of male sex, old age, a weight loss of more than 5%, pleuritic chest pain, poor performance status, abnormal haematological indices and sarcomatous histology (Edwards *et al*, 2000). Median survival times range from 5-16 months, (8 – 14 months in UK studies), and are related to histology, Table 1.2. Patients who present with dyspnoea but no pain survive twice long as those with pain (Antman *et al*, 1980).

Most patients with mesothelioma deteriorate rapidly from presentation apart from the small number with very localised disease who are suitable for radical surgery. Alongside dyspnoea and complex pain, weight loss, sweating, deteriorating lung function and fatigue are common, Table 1.3. Recurrent pleural effusions necessitate admission to hospital for aspiration and talc pleurodesis is recommended to prevent further recurrence (Petrou *et al*, 1995). Tumour tracking along thoracoscopy or pleural aspiration ports is common, often producing painful chest wall swellings; prophylactic radiotherapy can prevent this in the majority of cases. The pleural 'rind' tends to encase the lung

and, as it thickens, immobilises and constricts the ipsilateral hemithorax (BTS, 2001).

## **1.3 Treatment and palliation**

### *The place of surgery*

Radical surgery, extrapleural pneumonectomy, is a drastic measure in which the pleura, pericardium and ipsilateral diaphragm are removed in an attempt to remove all the tumour. Surgery is only appropriate in cases that present with early, localised disease but unfortunately staging is not very accurate and in 20 – 25% of patients selected for radical surgery the disease is found to be inoperable (Rusch *et al*, 2001). Multimodality treatment, that is surgery in combination with chemotherapy and radiotherapy, may increase survival times, but this has not been established by a randomised controlled trial (Sugarbaker *et al*, 1996; Treasure and Sedrakyan, 2004) but fewer than 5% are diagnosed sufficiently early for this approach. Debulking surgery, decortification or pleurectomy, may improve respiratory function and symptoms and it may improve survival by reducing the tumour load (BTS, 2001).

### *Oncological interventions*

There is no standard chemotherapy in mesothelioma in the UK because results to date are disappointing; any treatment tends to be part of a clinical trial (see the next section). Not surprisingly, patients are not easily recruited to trials (Chapman *et al*, 2006). A recently-introduced anti-folate agent, pemetrexed, plus an older drug, cisplatin, is currently standard treatment in North America and much of Western Europe. The NHS initially refused funding for pemetrexed, but a recent appeal was successful and this treatment is now available for UK patients, pending a final decision later in 2007 (NICE<sup>1</sup>, 2007), (see next section). Radiotherapy does not affect prognosis but is recommended to reduce tumour tracking along thoracoscopy ports. It may relieve pain in 50% of cases, but at the unacceptable cost of radiation effects on lung tissue (Ariza and McBeth, 2004).

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<sup>1</sup> NICE is the National Institute for Health and Clinical Excellence, the organisation responsible for the assessment of new medications and technologies for the NHS.

## *Current trials*

As described above, mesothelioma is notoriously unresponsive to chemotherapy agents; pemetrexed is the only agent licensed for use in mesothelioma. Kindler (2000:313-326), reviewing chemotherapy trials in mesothelioma, stated that *'it is unclear whether any intervention has had a significant impact on more than a few highly-selected patients'*. Although partial response, up to 20%, to combination chemotherapy has been reported in up to a third of patients with mesothelioma, this tends to relate to carefully-selected patients with early disease. The response, normally in terms of improved CT scan appearances, does not usually relate to improved survival times (Nowak *et al*, 2002; Vogelzang *et al*, 2003). However, Kindler's 'cautious optimism' regarding newer agents may be supported by a recent trial of pemetrexed in combination with the platinum-based drug, cisplatin, compared with cisplatin alone (Vogelzang *et al*, 2003). This trial, involving 448 recruits, showed benefits from the pemetrexed/cisplatin combination in median survival (12.1 v 9.3 months), median time to disease progression (5.7 v 3.9 months), and response rate (41% v 17%). The trial also revealed the need for vitamin supplementation to reduce toxicities. However, although the results are encouraging, survival is still short and virtually all patients die within 18 months. The MSO1 trial, Table 1.4, is designed to determine whether palliative chemotherapy is more effective than 'active symptom control'; it is due to report in 2007 (Muers *et al*, 2004).

Early results from animal studies using oncolytic herpes simplex virus treatments have been encouraging and a small study using herpes simplex virus thymidine kinase 'suicide gene' into the pleural space in combination with systemic ganciclovir resulted in long-term survival, more than 6.5 years, in two of 21 patients (Serman *et al*, 2005). Treasure and Sedrakyan (2004), in reviewing treatment options, conclude that:

*'Mesothelioma has largely defeated treatment. Radical treatments, occupying the 3 months after diagnosis, can take up the best 3 months that the patient might have had.'*



Contrastingly, Steele and Rudd (2006:297) state that

*'We now know that it [chemotherapy] can be beneficial when used judiciously in appropriate patients'.*

<b>Trial</b>	<b>Summary</b>	<b>Status</b>
MSO 1	A randomised controlled study of comparing 3 treatments: active symptom control (ASC) alone or with 1 or 3 chemotherapy agents (Vinorelbine or, in combination, mitomycin, vinblastine and cisplatin).	Ceased recruiting 2006
MesoVATS	A comparison of medical talc pleurodesis with video-assisted thoracoscopic talc pleurodesis	Recruiting
MARS (Mesothelioma and radical surgery)	To determine whether radical surgery (extrapleural pneumonectomy) with chemotherapy and radiotherapy provides improves survival and quality of life compared with other standard treatments	Recruiting
MALCS (Mesothelioma and lung cancer)	Population-based case-control study of mesothelioma and lung cancer in British adults under 60 years of age	Recruiting

**Table 1.4: Current mesothelioma trials in the UK**

### *Palliative and supportive care*

In the face of a rapidly progressive malignancy, the early introduction of palliative and supportive care is recommended in mesothelioma, (BTS, 2001), (Boxes 1.6 and 1.7). There are no reports in the medical literature documenting the palliative care needs of mesothelioma patients and their families. Referrals of *lung cancer* patients to palliative care teams are variable and often occur relatively late in the illness (Krishnasamy and Wilkie, 1999:131) but there is no information concerning the referrals in mesothelioma.

In more common cancers, knowledge of the disease impact on patients and their families has made a real difference to our understanding of the condition and to the development of appropriate health services (National Cancer Alliance, 1996; Greer and Watson, 1987). Oral histories of people with mesothelioma describe the devastating impact of the diagnosis and the effects

of the illness on patients, their families and local communities (Johnston and Mclvor, 2000:177-208; Walker and LaMontagne, 2004).

Many studies have demonstrated that the major unmet needs of cancer patients concern psychosocial issues and communication (Thomas *et al*, 2001; Hill *et al*, 2003; Heaven and Maguire, 1997). Patients with lung cancer have been shown to experience more psychosocial problems than patients with cancers in other sites, (Houts *et al*, 1986; Zabora *et al*, 2001), but there are few data relating to mesothelioma. A quality of life study during chemotherapy for mesothelioma revealed that scores relating to role and social functioning were 'surprisingly high' (that is, worse) in comparison with lung cancer (Nowak *et al*, 2004).

Improvements in communication in order to address the information needs of lung cancer patients and their families have been called for (Krishnasamy and Wilkie, 1999: 73; Hill *et al*, 2003). Family members and other close informal carers of cancer patients may experience severe, but often overlooked, distress (Kristjanson and Ashcroft, 1994). Lung cancer patients' concerns about their families and the impact of the illness on them have been shown to rank only second to patients' concerns about their illness (Hill *et al*, 2003). Health service providers are increasingly being advised to consider the needs of families/carers as well as patients in planning services (Grande *et al*, 1998; Speice *et al*, 2000; National Cancer Alliance, 1996; Soothill *et al*, 2001).

The disease trajectory in mesothelioma has not been specifically described but the frequency of recurrent effusions would suggest that it is likely to be more erratic than the steady decline of most malignancies in the final year of life (Murray *et al*, 2005). Concerns have been expressed about lack of medical knowledge of mesothelioma, even in areas of high incidence (Johnston and Mclvor, 2000:179-87). In addition, as mesothelioma is a prescribed industrial disease, patients are entitled to specific State benefits and the majority are also eligible for civil compensation but both claims processes may be complex and stressful (Wikeley, 2000). Finally, as deaths from mesothelioma are 'unnatural' in law, a Coroner's investigation is necessary involving a post mortem

examination and inquest that add to the burden on relatives (Downs *et al*, 2002).

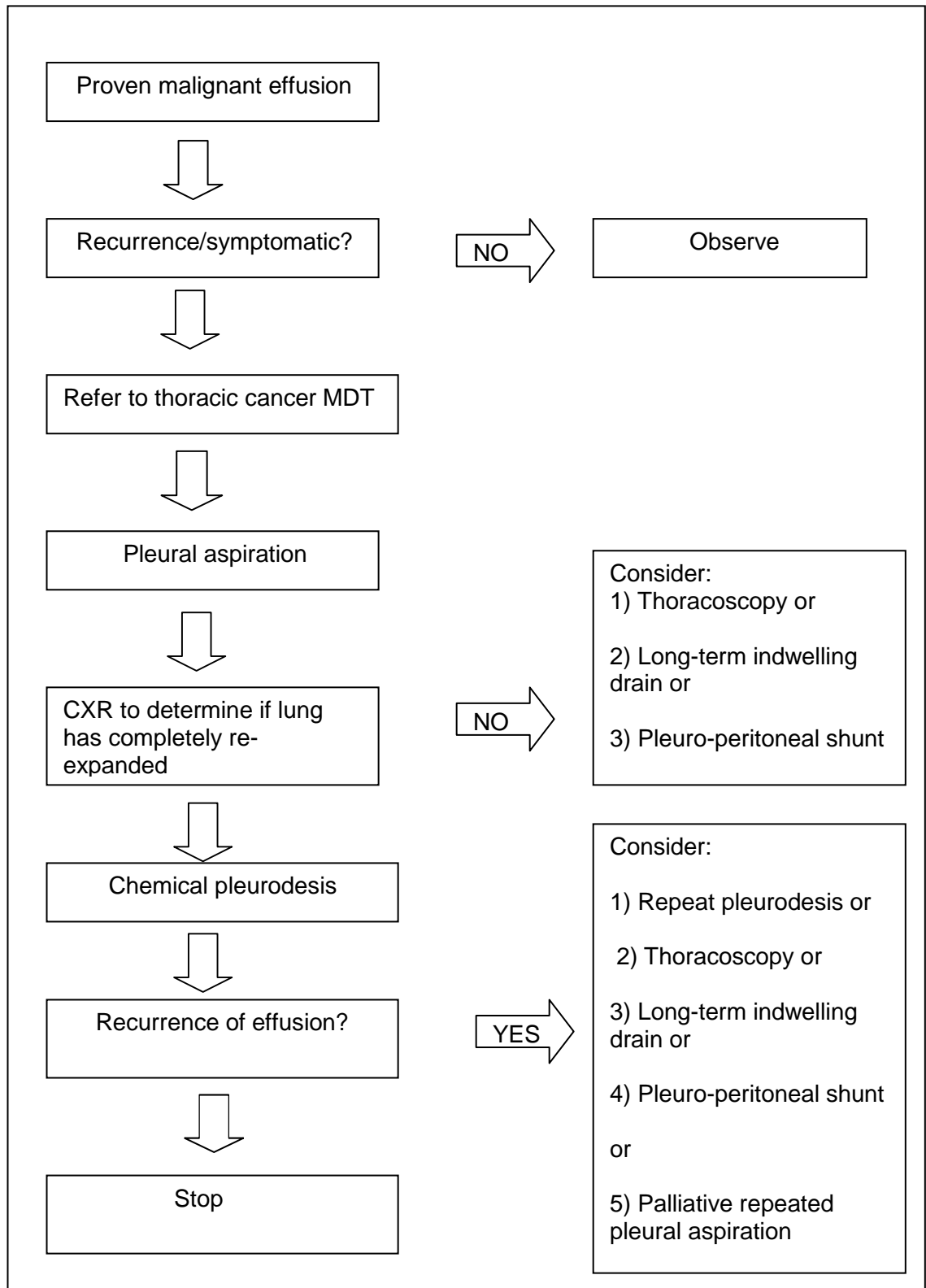
The main physical symptoms in mesothelioma are similar to those of lung cancer with breathlessness, pain and fatigue predominating. Haemoptysis, lymphadenopathy and problems due to metastases are less common in mesothelioma (Cooley, 2000; BTS, 2001; Edmonds *et al*, 2001).

Breathlessness management depends upon the underlying cause. Symptomatic pleural effusions should be aspirated using an ultrasound or CT-guided technique and, if recurrent, chemical pleurodesis should be performed with the intention of causing an inflammatory response resulting in adherence of the visceral and parietal pleural membranes, Box 1.2 (Antunes *et al*, 2003). Talc is more effective than tetracycline, (90% v 75%), for pleurodesis (Petrou *et al*, 1995). Pleurodesis is more effective if performed early, that is, before the lung becomes unable to re-expand due to tumour. If both the lung and mediastinum are fixed, this limits the volume of an effusion. If the lung is fixed but the mediastinum and diaphragm are mobile, fluid can accumulate and may compromise the contralateral lung; in this situation VATS or open pleurectomy may be required. Complications of repeated pleural aspirations include lung collapse, lung infection and empyema (pleural abscess). In addition, insertion of a chest drain is painful and frightening (Shaw and Agarwal, 2004; Drain and Wells, 2006).

Another option for recurrent effusions, when pleurodesis is unsuccessful or impractical, is the insertion of a long-term chest drain that can be managed by patients at home. This often causes pleurodesis. The indwelling drain abolishes the need for repeated aspirations and gives the patient more control over the situation (Burgers *et al*, 2006). Pleuro-peritoneal shunts have become unpopular due to the tendency for peritoneal disease to develop (Martin-Ucar and Waller, 2006:259-60).

Pericardial involvement may result in a potentially fatal pericardial effusion. Management depends on rapid diagnosis and referral to a cardio-thoracic unit

for consideration of drainage in the first instance followed possibly by pericardectomy or other longer-term drainage procedure (Laham *et al*, 1996). Non-pharmacological treatments of dyspnoea are discussed in the next section.



**Box 1.2: Management of malignant pleural effusions, (Antunes *et al*, 2003).**

Although pain in mesothelioma is acknowledged to be severe and complex, often with neuropathic components, there is no consensus about best management. Mercadante *et al* (2000) demonstrated that opioid requirements in mesothelioma continue to increase throughout the illness, and escalate more than in other malignancies, although the opioids considered in this study were restricted to dextropropoxyphene and morphine. It follows that alternative opioids with a broader mode of action such as methadone or fentanyl should be considered for complex pain in mesothelioma, alongside adjuvant analgesics (Ahmedzai and Clayson, 2006). A variety of nerve block procedures, usually performed by pain specialists, may be helpful when medication is ineffective or limited by side effects, including percutaneous cervical cordotomy (BTS, 2001; Jackson *et al*, 1999).

### *Non-pharmacological therapies*

Patients who experience breathlessness often become anxious, sometimes to the point of panic attacks, resulting in a vicious cycle. Breathing control techniques, taught to patients by skilled nurses or physiotherapists, have been shown to be effective in reducing the symptom burden and empowering patients to regain a sense of control thus improving quality of life (Corner *et al*, 1996). However, effective non-pharmacological interventions are not offered to the majority of lung cancer patients (Hopwood and Stevens, 1995; Bredin *et al*, 1999; Edmonds *et al*, 2001); there are no data relating specifically to mesothelioma.

## **1.4 Living with a diagnosis of mesothelioma**

### *Reactions to the diagnosis*

Some patients with mesothelioma may have lived with 'anticipatory anxiety' for years prior to developing the disease, the so-called 'Damocles syndrome' (Barak *et al*, 1998; de Villiers *et al*, 1997). In high-risk occupational groups, such as shipyard metal plate workers, it is common for patients to know of work colleagues who have succumbed to mesothelioma. Barak *et al* (1998) found that 50% of 16 electrical plant workers who had been diagnosed with asbestosis

suffered post-traumatic stress disorder following the diagnosis, related to their increased risk of subsequently developing mesothelioma. The Asbestos Regulations (1968) that included risk information to protect the workforce, were slow to be implemented and penalties for infringements were small (Tweeddale, 2000:207-8; Johnston and Mclvor, 1999:129-33). Media reports may have informed older workers who had not received any official risk information whilst working. In the notorious Wittenoom asbestos mine in Western Australia, miners were misled about the reason for the deaths and disease that they saw affecting fellow workers: they were told the cause was tuberculosis, although many of them suspected that asbestos dust was a health hazard (Cappelletto and Merler, 2002). Younger patients may have had health and safety information at work but often thought 'it won't happen to me'. Denial has been described as a common coping mechanism for dealing with the anxiety provoked by risk information and may be related to the fatalistic 'macho' culture of the predominantly male workforce (Johnston and Mclvor, 2000:171, 212-3, 221). However, patients who first have pleural plaques may be particularly anxious about their risk of mesothelioma, because the chest x-ray provides visible evidence of asbestos exposure and there is a common misconception that mesothelioma may develop from pleural plaques (Kazan-Allen, 2006).

Most people are shocked by the diagnosis; many may have forgotten or suppressed their history of asbestos exposure many years ago and then have to try to deal with the reality of having a terminal disease (Walker and LaMontagne, 2004). Lebovits (1985) described denial of the danger and minimisation of personal exposure as common reactions in patients diagnosed with mesothelioma alongside emotional responses. Anger has been described as a common reaction in mesothelioma patients as well as 'stoical fatalism' and 'passive resignation' (Lebovits *et al*, 1981; Johnston and Mclvor, 1999:221-3).

Anger may have several foci: 1) the employer/s for allowing unsafe practice, 2) the government for being slow to introduce legislation and then failing to monitor industry adequately, 3) the medical profession for the common delays in diagnosis, clumsy breaking of bad news, traumatic investigations and interventions, lack of curative treatments and inadequate support (Walker and

LaMontagne, 2004). Displaced anger towards the medical profession may represent part of the emotional turmoil that patients with this disease face. Anger, guilt and remorse may be self-directed and then contribute to despondency and depression (Lebovits, 1985; Faller *et al*, 1995). A study comparing psychiatric illness between mesothelioma patients, pipe-coverers at risk of, but not suffering from mesothelioma, and a control group, demonstrated a depressive disorder in 45% of the mesothelioma patients (Lebovits, 1985).

Stoicism in the face of terminal illness reflects the cultural norms of the post war era and the 'macho', risk-tolerating and fatalistic attitudes of men of the 'traditional working class' (Johnston and McIvor, 2000:171, 220-1). It also serves to reduce the stigma associated with malignant disease by presenting the patient as in control, respectable and unemotional - all positive features of traditional masculinity (Moynihan, 1998). In this context 'stoicism' relates to an approach to adversity based on the classical stance in which the person adopts an uncomplaining, heroic attitude, typified by the 'stiff upper lip'. In contrast, 'fatalism' reflects a belief set in which a person perceives events as essentially outside their own control, unchangeable and therefore not their own responsibility; sometimes associated with belief in a higher power and/or a preordained destiny. The stoical reaction or coping style reported in patients with mesothelioma (Lebovits *et al*, 1983, Lebovits, 1985) may well be associated with fatalistic beliefs concerning risk and illness.

Psychosocial distress in malignancies has been linked to the disease site and the associated symptom burden. Patients with lung cancer are known to suffer the most psychosocial distress but mesothelioma has not been investigated specifically (Zabora *et al*, 2001; Houts *et al*, 1986; Nowak *et al*, 2004). However, as one study demonstrated that symptom scores for pain are higher in mesothelioma than in lung cancer, and scores for social role and functioning were also worse than in lung cancer, (Nowak *et al*, 2004), it is reasonable to assume that mesothelioma is likely to cause as much, if not more, psychosocial distress than lung cancer, given the similar site and more severe pain.

## *Attribution*

Attribution of mesothelioma to asbestos exposure appears to be complex. Patients with mesothelioma may have difficulty in accepting that asbestos has caused their illness. There are several reasons for this disbelief: 1) there is a general lack of public awareness of mesothelioma; 2) it is still a relatively rare disease and historically has clustered in areas around related industries; 3) the long latency period of 30-50 years makes the link between cause and effect seem tenuous; and 4) in some cases, asbestos exposure may have been brief but heavy, such as working for a few months as an apprentice (Lebovits 1985, Lebovits *et al*, 1981). In some patients the exposure may have been environmental or paraoccupational, in which case the patient may feel the risk was too small to believe; this is sometimes referred to as 'bystander' exposure. In these cases the asbestos may have been in the atmosphere from neighbouring factories or on work-clothes that were laundered at home.

Accepting causal attribution to asbestos leads to several associated problems. The blame for exposure implicates the employer and in many cases the workforce in post-war Britain was loyal and/or indebted to their employer/s in an era of job insecurity and financial hardship (Johnston and McIvor, 2000:220). Similarly, Australian asbestos miners in the 1970s were more concerned about keeping their jobs than heeding emerging reports of asbestos health hazards (Walker and LaMontagne, 2000). South African asbestos mine workers demonstrated against mine closure because they had no other employment prospects locally (Kisting, 2006). Lebovits' (1985) US study of 38 patients with mesothelioma reported that 65% denied any feelings of anger towards the asbestos industry.

In the heyday of British manufacturing it was common for two or three generations to follow each other into the local manufacturing or engineering industry and the older patient with mesothelioma may realise that he has encouraged younger relations to follow his footsteps into a potentially deadly



trade. In one study 78% of asbestos workers had a family member in the same trade (Lebovits, 1985). Some patients with mesothelioma may feel guilty for unsafe work practices even if they had no knowledge of the hazards at the time (Lebovits, 1985; Lebovits and Strain, 1984). Walker and LaMontagne (2004) cite avoidance of the issue as a strategy to reduce emotional distress. However these authors also emphasise the difference between past and current workers: current workers are very aware of health and safety issues concerning asbestos and insist on their implementation.

The alternative blame laid on tuberculosis by the Wittenoom mine managers may have inadvertently served the Australian miners as well as their employers by reducing both feelings of personal responsibility in the person with mesothelioma and the responsibility on the part of the employer. The narratives of affected Italian migrant asbestos miners report that they were very concerned about the extremely dusty conditions in which they worked in Wittenoom, knew that workmates were dying, knew of silicosis from dust and yet still accepted tuberculosis as the official cause of deaths and illness. However the study also reveals that, with hindsight, ex-miners remain puzzled as to why they did not realise the risks at the time (Cappelletto and Merler, 2003). Attribution theory describes 'false attributional errors' as a device for reducing emotional distress (Kelly, 1973). However it appears that, in the case of Wittenoom, the false attribution to tuberculosis, promoted by the management and apparently reinforced by the medical establishment, may have been at least in part a deliberate ploy to minimise commercial risk (Cappelletto and Merler, 2003).

Patients with lung cancer are shown to frequently question the importance of smoking as the causative agent or to offer alternative explanations which served to minimise its impact, Faller *et al* (1995). The authors suggest that these alternative explanations or 'false attributional errors' are developed in order to reduce self-blame, a similar conclusion to that of Kelly (1973). Faller *et al* (1995) also explored the uncertainty about the relationship between attribution and adjustment: on one hand, attribution to an external agent may

help to reduce personal responsibility for the illness, on the other, it is clear that many patients with mesothelioma do exhibit feelings of guilt and remorse, albeit often inappropriately in the social context of their working lives (Lebovits, 1985).

### *Loss of self*

The diagnosis of a terminal disease has been described as a threat to the integrity of self and part of this complex notion is deterioration in body image and function (Brennan, 2001; Lawton 2000:87-105). This may be particularly hard for male patients with mesothelioma because for many of them, having worked in physically demanding jobs, a muscular physique and physical fitness were their 'capital' (Connell, 1995:54-6). Narrative accounts from men with asbestos-related disease reveal that watching their wives doing stereotypically male tasks at home, such as digging the garden or even driving the car, and the impact on social activities such as dancing, caused additional distress to men from these traditionally configured families (Johnston and McIvor, 2000:177-200). Walker and LaMontagne (2004) reported that loss of the ability to undertake DIY tasks, travel, and participate in social events reinforced the loss of normality. An investigation of quality of life issues in patients undergoing chemotherapy for mesothelioma, (m=45, f=8), highlighted particular impairments: role and social function were 'worse than expected' by the authors, in addition to the anticipated physical problems of dyspnoea, pain and cough (Nowak *et al*, 2004). Breathlessness and weight loss, both common visible manifestations of mesothelioma, cannot be concealed and may also cause impaired sense of self and body image (Goffman, 1963:64-8).

### *Locus of control*

A diagnosis of cancer may force patients to confront their loss of control over events and challenge fundamental assumptions about their world such as notions of deservedness, justice, fairness and health beliefs. Many studies have demonstrated that individuals tend to have an inflated belief in their ability to control their own existence and the world they live in, believing that they actually

hold the locus of control. Those who appear to have most control, relating to wealth and position in society, may find the loss of control precipitated by illness hardest to bear (Park and Folkman, 1997). Patients may feel that they surrender autonomy to the medical authorities which may result in loss of control on a personal level. Deteriorating bodily functions, and treatment and monitoring regimes, further emphasise the loss of control and the major change in circumstances (Costain Schou and Hewison, 1999: 138-52).

Bolam *et al*, (2003) explored the psychosocial aspects of health inequalities such as sense of control over health and described the complexities of agency in people from lower socio-economic groups. They reported that, although these groups may exhibit a fatalistic belief with regard to their perceived limited control over their own health, individuals' accounts also illustrated areas in which they made efforts to retain a sense of control such as taking care of themselves. This contrasts with the risk-taking macho culture prevalent in the industries relevant to this study (Johnston and McIvor, 2000:171, 212-3).

## **1.5 Supportive services for cancer patients and their families**

### *Policy and palliative and supportive care services*

Palliative care, encompassing a holistic approach to the care of patients, initially relating to cancer but now proposed to apply to all 'end-of-life' conditions, has been evolving in the UK since the birth of the modern hospice movement in the 1960s (Seale, 1998:113-7, Clark *et al*, 2005:3-4). The current definition, in Box 1.3, (NICE, 2004:20) was based on earlier work from the World Health Organisation and the National Council for Hospice and Palliative Care. Recently it has been acknowledged that some elements of palliative care should be provided earlier in the disease in order to address identified needs of

cancer patients and their families and these have been grouped together as supportive care, Box 1.4 (NICE, 2004:19).

**Box 1.3: Definition of palliative care (NICE, 2004:20)**

**Palliative care** is: ‘...the holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.’

‘Palliative care is based on a number of principles, and aims to:

- Provide relief from pain and other distressing symptoms
- Integrate the psychological and spiritual aspects of patient care
- Offer a support system to help patients to live as actively as possible until death and to help the family to cope during the patient’s illness and in their own bereavement
- Be applied early in the course of the illness in conjunction with other therapies intended to prolong life (such as chemotherapy or radiation therapy), including investigations to better understand and manage distressing clinical complications.’

**Box 1.4: Definition of supportive care (NICE 2004:19)**

**Supportive care** ‘...helps the patient and their family to cope with cancer and treatment of it – from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease. It is given equal priority alongside diagnosis and treatment.’

Supportive care encompasses:

- Self help and support
- User involvement
- Information giving
- Psychological support
- Symptom control
- Social support
- Rehabilitation
- Complementary therapies
- Spiritual support
- Palliative care
- End-of-life and bereavement care

In the UK, specialist palliative care (Box 1.3) is provided by multi-disciplinary teams, ideally including healthcare professionals from palliative medicine, palliative care nursing, physiotherapy, occupational therapy, and psychology augmented by social workers, dieticians, complementary therapists and ministers of religion. General palliative care is seen as being the role of GPs and their teams, community and hospital nurses. Specialist palliative care aims to provide care for patients with complex symptoms and requires knowledge of advanced symptom control. There are some difficulties with these intentions in practice because patients' conditions can change rapidly, their needs are often not predictable, and provision of specialist palliative care is patchy. Moreover, the role of palliative medicine specialists and when to refer patients to them, particularly with non-cancer conditions, has been found to be poorly understood by colleagues, and this may partly explain the tendency for late or insufficient referrals (Hanratty *et al*, 2006).

Supportive and palliative care needs of patients have tended to be approached from the perspective of healthcare professionals but recently there has been more attention around accessing patients' definitions of their needs; the participation of patients in shaping health services is now UK policy (Department of Health, (DH), 2004, 2006a), although this rhetoric is not yet reflected in standard practice. In addition it is now accepted that provision of clinical investigation and treatment should be complemented by a range of supportive services that address the psychosocio-emotional impact of cancer. There is evidence that by providing these additional services, outcomes in terms of patient satisfaction, health-related quality of life, psychological morbidity and survival are improved (NICE, 2004).

### *Service provision and usage*

A comprehensive strategy aimed at improving services for cancer patients was produced in the 10 year NHS Cancer Plan (Department of Health, 2000b) and developed in subsequent policy documents. Thirty four cancer networks were established, each serving a population of around 1-2 million people, and including both primary and secondary care organisations. Networks were intended to oversee the improvement of cancer services in each locality. At the

local level, cancer units, usually in District General Hospitals, provide basic investigations, some routine chemotherapy, and surgery if the unit is accredited for it. Regional cancer centres provide radiotherapy, chemotherapy including clinical trials, and more specialised surgery. Special centres were developed to cater for some rare or particularly complex cancers, although none are currently specific for mesothelioma.

One of the foremost initiatives was the development of the multidisciplinary approach to cancer, and cancer site-specific multidisciplinary teams (MDTs) were set up in each cancer centre and relating to the most common cancers. This approach aimed to ensure that investigations were conducted more efficiently, that treatment decisions were more consistent and that better outcomes were achieved (House of Commons Committee of Public Accounts, 2005). As mesothelioma is a relatively rare cancer, it is included in lung cancer MDTs in spite of it being a pleural tumour, and having many different features: these include aetiology, epidemiology, histological, pathological and clinical features, diagnostic difficulties, therapeutic interventions, psychosocial and medico-legal issues and not being amenable to similar treatments.

However, an evaluation of the progress of the Cancer Plan uncovered many problems to date:

*‘30% of Networks visited by the National Audit Office did not have comprehensive plans for providing cancer services in their locality.’*

Repeated reorganisations of health services, lack of resources, lack of monitoring and reporting arrangements, poor inter-agency relationships and a need for more prevention and health education are addressed in the report, which suggested that the Cancer Plan needs updating and tighter performance monitoring (House of Commons Committee of Public Accounts, 2005).

### *Needs of patients, families, and carers*

Former Australian power workers, exposed to asbestos at work, and their families, identified a range of unmet needs for people with asbestos-related diseases. These included hospice and palliative care services, and professional

counselling; the study also revealed a desire for *local* access to specialist respiratory medicine, radiotherapy, and equipment such as oxygen concentrators. This community study also indicated a need for public and GP education around asbestos and disease, (Walker and LaMontagne, 2004). Hawley *et al's* (2004) results were similar but also emphasised the need for better communication between professionals and patients, and between professionals. They proposed strategies to support dying at home, suggested that a specialist mesothelioma nurse should be involved with each patient, and stressed the need to support carers whilst caring and in bereavement.

There is a substantial body of literature confirming the major impact of caring for someone with terminal illness on family caregivers or informal carers, and national policies concerning carers have been introduced in the past decade (Nolan *et al*, 1997; Carers Act, 1995). Reports indicate that the unmet needs of family/informal carers of cancer patients may exceed those of the patients (Soothill *et al*, 2001; Higginson *et al*, 1990). Carers' unmet needs embrace information about the disease and its management, as well as practical, social, and emotional support. In mesothelioma there are additional stresses on carers relating to advocacy and information activities that relatives undertake relating to compensation procedures when patients are too ill to do these themselves (Johnston and McIvor, 1999:134-8; Walker and LaMontagne, 2004). In the UK, the coronial investigation of mesothelioma as an 'unnatural death' creates further distress for relatives (Downs *et al*, 2002).

Caring for a patient in the palliative stage of their illness reveals many unmet needs of carers; additional factors related to these unmet needs include carers in poor health, who are socially isolated, or not the spouse or partner of the patient (Soothill *et al*, 2001). In a study of lung cancer patients, although 67% of the patients described themselves as dependent on family and friends, only 29% of patients felt that their informal carers had particular needs relating to their illness (Krishnasamy and Wilkie, 1999:70). Paradoxically, in spite of evidence of substantial unmet needs of carers, the majority of the carers reported being satisfied with the support that *they* received; the authors suggest this reflects that carers accept the patients' needs as priority and that health

services reinforce this. Krishnasamy and Wilkie, (1999:87-9), also stress that much more attention must be directed towards supporting lay carers in order to fulfil the government's agenda to enable more people to die at home '*if caring is not to become an intolerable burden*'. Walker and LaMontagne, (2004), described the role of women carers in mesothelioma, given that most patients with mesothelioma are men, as support and advocacy, including medical care, and providing emotional support. Most reported an adverse effect on quality of life and exhaustion and social isolation due to caring for a dying husband at home. The authors described the carers' narratives as revealing 'extreme determination and strength'.

As care of dying patients at home becomes more prevalent due to initiatives encouraging patient choices around terminal care, the reliance on family members and close friends will increase. Patients with cancer tend to die in hospital (47%) or hospice/nursing home (17%) whereas more than 50% have expressed the wish to die at home (Higginson *et al*, 1998). Care of the dying at home depends heavily on family carers, yet 'carer collapse' or exhaustion is a frequent cause of inappropriate hospital admission of cancer patients in the terminal phase (Hinton, 1994; Higginson *et al*, 2006; Storey *et al*, 2003).

The recent guidance on palliative and supportive care (NICE, 2004) includes support services for informal carers and goes some way to addressing the ambiguous position of carers. Patients are also worried about the burden of care on their families: Hill *et al*, (2003), established that, after worries about their illness, patients with lung cancer were most concerned about the impact of their illness on their close family.

### *Self-help groups and the voluntary sector*

The UK tradition of charitable and voluntary action is extensively represented in healthcare: of the 166129 charities registered with the Charity Commission around 840 are cancer charities, (Charity Commission, 2006), and prominent amongst them are Macmillan Cancer Relief<sup>2</sup> and Cancer Bacup, both providing free information about cancer for patients and carers This information

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<sup>2</sup> The UK charity Macmillan Cancer Relief was renamed Macmillan Cancer Support in 2006



encompasses the various types of cancer, treatments, clinical trials, help available, financial advice and signposts patients and carers to other agencies. Macmillan Cancer Relief was the first UK charity to provide a support service specifically related to mesothelioma; it funded the Mesothelioma Information Service<sup>3</sup> that ran a telephone helpline from a Leeds hospital base and produced an information book (Robinson, 2003). In 2004 Macmillan Cancer Relief replaced the Information Service with a new organisation, Mesothelioma UK, based in Leicester. This charity is run by a Macmillan nurse consultant in mesothelioma and provides a newsletter, a telephone helpline, web-based information, ([www.mesothelioma.uk.org](http://www.mesothelioma.uk.org)), and promotes education relating to mesothelioma.

Support groups for people with asbestos-related diseases have developed in areas of high incidence and recently instituted a national forum under the auspices of Mesothelioma UK. Support groups have tended to focus on gaining financial benefits and compensation for their members; they are usually run by union representatives with support from legal firms. In line with the recommendation in a survey of lung cancer patients' support needs, that 'one stop' services are needed, (Krishnasamy and Wilkie, 1999:90), and after consultation with local patients, their families and professionals, a service commenced in 2005 in Barrow-in Furness: BARDS (Barrow Asbestos-Related Disease Support), Box 1.5.

There is a growing awareness of the value of support groups in providing a focus for a community response to asbestos-related diseases and this links to calls for public participation, particularly in affected communities, in the 'new public health' (LaMontagne and Walker, 2005; Petersen and Lupton, 1996:7).

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<sup>3</sup> An interview account of the Mesothelioma Information Service can be found in Box 6.6

### **Box 1.5: Barrow Asbestos-Related Disease Support (BARDS)**

A support group for people with asbestos-related disease and their families provided by St Mary's Hospice, Ulverston, Cumbria, and supported by local Trades Unions, the Benefits Agency, Citizens Advice Bureau and local and national legal firms. BARDS was set up after 2 open public meetings in which a Participatory Appraisal exercise was used to determine what local people wished to see developed to support people with mesothelioma and their families. As a result the following free services are available:

A monthly 'drop-in' session in Barrow-in-Furness:

- Open access to medical, nursing, benefits and legal advice – all practitioners have expertise in the care of people with mesothelioma. Healthcare staff work alongside colleagues in hospital and general practice
- Information service
- Breathlessness management sessions
- Complementary therapies
- Carer support programme
- Talks on mesothelioma and related topics
- Social activities
- 24-hour hospice helpline

## **1.6 Mesothelioma, the law and society**

In this section, financial assistance and medico-legal matters affecting patients suffering from mesothelioma are discussed with respect to: firstly, State benefits and secondly, civil compensation, and this is followed by an account of the procedures that follow the death of a patient due to mesothelioma.

### *State benefits*

In the UK, people with cancer are entitled to a considerable range of State benefits as part of the Social Security system designed to protect them, to some extent, from disadvantage due to ill health. These allowances commonly include Incapacity Benefit, Mobility Allowance, Attendance Allowance, Carers Allowance and also, in mesothelioma, Industrial Injuries Benefit (IIDB). This benefit applies if patients can: a) provide proof of the diagnosis, and b) provide proof of occupational exposure to asbestos when employed after 4<sup>th</sup> July 1948

in a *particular*<sup>4</sup> occupation. The latter requires details of past employment; the benefit does not apply to the self-employed or employers and does not apply if occupational exposure cannot be confirmed (Social Security Regulations, 1985). The Department of Social Security (DSS) may check these details with the listed firms, particularly if mesothelioma is suspected but not yet confirmed. However, many of the firms have gone out of business and so details cannot be confirmed. In these cases the claimant has to try to provide witnesses to corroborate the account of asbestos exposure. Many patients will have had multiple jobs and may have moved around the UK – it can be practically impossible to prove industrial asbestos exposure for some people and an added source of stress. The claimant needs to show that ‘on a balance of probabilities’ their occupation exposed them to substantial asbestos dust.

In some cases a posthumous claim has to be made, perhaps because the diagnosis of mesothelioma was only recognised at post mortem or the person was too ill to make a claim. A person acting on behalf of the deceased has to apply to be the ‘appointed person’ within 6 months of the date of the death certificate and then has a further 6 months in which to submit the claim. This may pose problems for the appointed person because they may well not know full employment details of the deceased and have to deal with this when newly-bereaved (Robinson, 2003; Social Security Act, 1975). When IIDB is awarded it is now automatically paid at the maximum rate based on a disability assessment of 100% in all mesothelioma cases (Gorman *et al*, 2004)

Of the people certified as dying of mesothelioma each year, it has been established that around a third do not receive IIDB but the total includes people who have no history of industrial asbestos exposure (approx 20%) and those who do not satisfy the criteria for the benefit (HSE, 2006c). A recent study demonstrated that less than 50% of cancer patients access all the benefits that they are entitled to and suggests that reasons include: lack of information, complex form-filling, self-reliance, suspicion of State bureaucracy and the distracting burden of serious illness (Macmillan Cancer Relief, 2004). Robinson’s (2003) mesothelioma information booklet provides details of the

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<sup>4</sup> Specifically, an occupation that is accepted by the Department of Social Security as likely to expose workers to asbestos.

benefits available and how to access them. However, for people who are ill and who also are from a generation that tended to be self-reliant and therefore unfamiliar and uncomfortable with claiming benefit, the benefits process can be overwhelming (Gorman *et al*, 2004), as also demonstrated in a study of patients with lung cancer (Chapple *et al*, 2004).

### *Civil compensation*

People who develop mesothelioma (or asbestosis) are entitled to take action against the employer for civil compensation. There is no national record of civil claims pursued by people with mesothelioma but it is known that claim rates are considerably higher for mesothelioma but lower for other asbestos-related diseases in the UK compared with the US (Durkin, 1994). Access to justice may be difficult: the claimants are ill and often fearful of legal proceedings and causation may be difficult to prove because evidence from past workmates may be impossible to obtain and many relevant insurance companies have ceased trading (Tombs, 2005). The legal process is therefore often slow and in the past many claimants have died before compensation has been agreed. Since 2002 arrangements have been in place in England and Scotland to 'fast track' mesothelioma claims, through the Queen's Bench Division, but this depends on patients' solicitors being familiar with the system (Kazan-Allen, 2004).

Civil compensation awards are based on lost years of life and suffering; they range between £45,000 and £75,000 for general damages plus care costs and financial losses, but in an exceptional case the award was £4.37 million (Budgen and Lipsitz, 2006:445). Under the Fairchild ruling, (Budgen and Lipsitz, 2006:444), claimants could sue a single negligent employer for the total compensation sum even when several employers may have been liable. This pragmatic ruling took into consideration the rapidly deteriorating health of the claimants, and the difficulty in chasing multiple employers and their insurers when many had gone out of business, were untraceable, or had not been insured. However it left several issues unresolved, such as whether or not joint and several liability was established. More recently a decision to overturn the Fairchild ruling caused great distress and anger amongst mesothelioma patients and campaigners as this meant that when multiple employers were

involved it was the patient's responsibility to attempt to sue them all and recover a proportion of the compensation from each employer. The result would have led to long delays in the settlements being reached and much less compensation being received by patients as they would not have been able to track many of those responsible. In response to an urgent plea for justice for people with mesothelioma and their families, this decision has now been reversed by new law that also grants retrospectivity (House of Commons General Committee on Delegated Regulation, 2006)

In the event of an eligible person being unable to recover damages from the employer, for example if the employer is insolvent, a statutory lump sum payment may be obtained under the Pneumoconiosis etc. (Workers' Compensation) Act (1979) and this is not restricted to particular occupations (London Hazards Centre, 1995:111). Service and ex-service personnel are not entitled to common law compensation for asbestos-related diseases due to exposure before 1987, although they are entitled to smaller financial allowances under War Pension arrangements (SARAG, 2004).

The massive financial toll of international asbestos-related civil compensation claims contributed to the near-collapse of the insurance giant, Lloyds of London (London Hazards Centre, 1995: 99). Asbestos related claims are escalating and therefore insurance companies underwriting the employers are prepared to robustly challenge any claims. The predicted total claim against insurers of the responsible employers is potentially devastating: an estimate of £8 – 20 billion was made in 2004, 75% of which would be claims relating to pleural plaques. However the UK Court of Appeal has just overturned 20 years of case law and disallowed claims for compensation for pleural plaques; this has been seen as a victory for the insurance companies. Unusually, the judgement included permission for an appeal; this is due to occur in 2007 (Daley J 2004, Kazan-Allen, 2006).

Criticisms of the asbestos industry allege ways in which the asbestos industry attempts to limit compensation payments, for example by manipulating bankruptcy laws and petitioning for capping of the global compensation pool

(London Hazards Centre, 1995:97-100). A test case in 1995, *Margerson and Hancock v J W Roberts Ltd* (1995), established the principle of liability in negligence to members of the public who develop mesothelioma due to neighbourhood asbestos exposure, in this case from an asbestos factory that contaminated the locality including a school.

### *Mesothelioma as 'unnatural' death*

In the UK, death due to mesothelioma is classed as an 'unnatural death' and, by law, has to be investigated by the Coroner (or Procurator Fiscal in Scotland) in order to ascertain the official cause of death. Unfortunately, at present, the law concerning the investigation of 'unnatural deaths' does not discriminate between (usually) expected deaths due to an industrial disease such as mesothelioma and a sudden unexpected death due to a criminal act. The procedures for investigating 'unnatural death' due to mesothelioma can, if handled insensitively, cause much additional distress to bereaved relatives. (Downs *et al*, 2002; Human, 2002). In the UK, the confirmation of death due to industrial disease rests with *individual* coroners and, in the absence of national guidance, there is no systematic assessment of mesothelioma cases, leading to inconsistent results and loss of financial benefits for some families (Kazan-Allen, 2005).

The doctor who confirms the death is required by law to contact the Coroner, usually via the Coroner's officer, an officer of the law. The confirming doctor is not entitled to issue a death certificate that would confirm the cause of death, even when there is no doubt that death was due to mesothelioma, because, technically, in the case of an 'unnatural death, the cause can only be determined by a Coroner after appropriate investigation. The Coroner's officer is usually a policeman who has received extra training related to coronial investigation. However, it may be an inexperienced young officer in uniform who attends or one who has never heard of mesothelioma and treats the situation as a 'suspicious' or 'sudden unexpected' death, even when the diagnosis has already been established and the death is expected (Downs *et al*, 2002). The relatives are required to make a formal identification of the body and give a

statement with particular reference to the occupational history of the person who has died. In most instances, the Coroner will request a post mortem examination that usually takes place in a local hospital mortuary; relatives are not able to refuse this. Samples of tissue are removed for analysis of asbestos fibres and subsequently the relatives may be asked how these samples should be disposed of – a consequence of recent organ retention scandals in the UK (Burton and Wells, 2002). The Royal College of Pathologists (2000) has produced an information pack for relatives about the procedure and purpose of post mortem examination.

The inquest, a formal procedure in court, is opened to herald the start of the investigation into the cause of death. The inquest is then adjourned until some weeks later when all the evidence has been gathered. On adjournment the Coroner releases the body to the funeral directors and the funeral can proceed, after a delay of usually a few days. The inquest hearing may occur many months after the death and the relatives are expected to attend. For many, the court procedure is threatening and unfamiliar. Worry about the inquest hangs over grieving relatives, and the award of civil compensation is often delayed as this may depend on the outcome of the inquest. Understandably, it is hard for recently bereaved people to cope with the investigation and frequent delays in the proceedings while tissue is analysed and employment records checked. In Scotland a group of palliative care physicians have influenced the Procurator Fiscal<sup>5</sup> and changed practice regarding mesothelioma deaths, thus reducing distress to relatives (Downs *et al*, 2002).

Many relatives are not made aware of the required legal procedures before the death and this understandably causes distress. There is no agreed national protocol or guidance on this matter, although some organisations in high incidence areas have developed their own systems (Downs *et al*, 2002). A UK survey confirmed that most relatives would prefer to be prepared in advance of the death but that this is often overlooked (Human, 2002).

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<sup>5</sup> The Scottish Procurator Fiscal is the equivalent of the Coroner in England and Wales.

A review of coroners' services, as part of the Shipman<sup>6</sup> enquiry, has made recommendations that could benefit relatives of people with mesothelioma. These will include giving bereaved people the right to raise concerns with coroners, clear legal rights, fewer delays, better communication, and information on support including bereavement services to be detailed in a coroners' charter (Department for Constitutional Affairs, 2006).

## 1.7 The tradition of social medicine

Social medicine developed in the mid-19<sup>th</sup> century and concerns the relationship between social factors and ill-health, alternatively described as 'medicine in the matrix of society' (Oakley, 1997). A classic text published by Virchow, a radical German physician, in 1849, described the social factors involved in the 1848 typhus epidemic in Upper Silesia, Germany and, for the first time, suggested a social solution rather than a medical one. He proposed and then implemented a revolutionary programme of social change involving improved employment and higher wages, provision of state education for all and the development of local rural cooperatives. This formed part of the Medical Reform Movement of 1848. Virchow stated that '*If disease is an expression of individual life under unfavourable conditions, then epidemics must be indicative of mass disturbances of mass life.*' (Taylor and Rieger, 1985)

Social medicine's promotion of the interplay between social circumstances and illness has had mixed fortunes, at least in part, because campaigners for social justice have frequently been in direct opposition to major political and economic forces (Waitzkin, 2001). The German social medicine movement started by Virchow grew to become a threat to the income and status of private medical practitioners and Virchow was briefly suspended when his political activities were seen as inappropriate for an eminent physician (Virchow, 2000). In the 1930s, medical support for the Nazi Party resulted in the destruction of the forerunners of today's health-maintenance organisations and replaced them

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<sup>6</sup> Shipman was a notorious GP who was convicted for the murder of 15 of his patients. He was imprisoned in 2000 and he committed suicide in prison in 2004. As a result of his criminal activities a comprehensive investigation, including Coroners' services, was undertaken.



with profession-dominated rather than patient-centred services (Waitzkin, 1998; Light *et al*, 1986).

In England in the 1940s, a group of doctors and scientists, with interests linking social factors and disease, formed the Committee for the Study of Social Medicine. The group produced several papers on social medicine topics but then dissolved during the Second World War when its London base was bombed during the Second World War (Watts, 2001). Morris and Titmuss, leaders in UK social medicine, became friends in the 1930s and collaborated initially on investigating the causation of coronary heart disease. Morris, a medically trained epidemiologist, worked in public health before war service in India as an officer in the Royal Army Medical Corps. Titmuss, who left school at 14 with no qualifications, pursued a self-taught study of social topics that led to a wide range of academic publications<sup>7</sup> concerning health inequalities and finally his appointment as Professor in Social Administration at the London School of Economics. After the war, Morris and Titmuss set up the Social Medicine Research Unit, funded by the Medical Research Council. This unit was charged with the ambitious task of determining all the social factors involved in disease, known as the 'Social Medicine Project'. Not surprisingly, this was not completed, although papers were produced concerning the social factors, mainly relating to poverty, linked with rheumatic heart disease, juvenile rheumatism and peptic ulcer (Oakley, 1996; Watts, 2001; Berridge 2001). The unit closed when Morris retired in 1975. Titmuss and Morris both held high-level national appointments and were influential in developing social policies of the Labour governments of the 1960s. Morris was involved with setting up the National Health Service and was also responsible for creating the modern community physician from the previous role of the Medical Officer of Health (Ashton, 2000a). The Society for Social Medicine continues the tradition but acknowledges an increasing blurring of boundaries between social medicine, epidemiology and the 'new public health', as discussed later (McPherson and Dunnell, 2002; Holland, 1994)

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<sup>7</sup> Books by Titmuss include *Poverty and Population* (1936), *Birth, Poverty and Wealth* (1943), *Problems of Social Policy* (1950), *Essays on the Welfare State* (1958), *Commitment to Welfare* (1968) and the US best-seller: *The Gift Relationship* (1970).

In the USA, Parsons (1951) described sickness as a social phenomenon and emphasised the adverse effects of illness on the effective performance of social roles that underpin a successful society. He regarded medicine as a controlling instrument that served to stabilise society. The Cuban revolution in the 1960s was inspired by the experiences of Che Guevara, doctor and political activist, who saw at first hand the need to improve the social conditions of the population in order to improve health. He described this process as 'revolutionary medicine' (Waitzkin, 2001).

A social medicine approach to mesothelioma illustrates the importance of social and economic factors in the continuing increase in incidence, in spite of the enormous reduction in industrial use of asbestos. Implementation of workplace Health and Safety regulations relating to asbestos has certainly reduced the traditional occupational risks of asbestos exposure dramatically (Hilliard *et al*, 2003). However, it is estimated that two thirds of all UK commercial buildings, approximately 850,000, contain asbestos, as do many public buildings and private homes, including many schools and hospitals built before 1975; some of the material is inevitably in a deteriorating condition (Health and Safety Executive, 1998; Tudor, 2001). The health risks to building construction and maintenance workers exist because Health and Safety regulations may be ignored, particularly in the many small firms that often employ sub-contractors. Asbestos removal firms have also been criticised for unsafe work practices. Enforcement of the regulations has been compromised by a reduction in the number of HSE inspectors in the past decade (London Hazards Centre 1995:70-73). Added to this is a general lack of knowledge about asbestos hazards and the difficulty in identifying asbestos-containing materials. The often casual workforce is by definition transitory and predominantly male; risk-taking is part of the 'macho' culture. Ironically, these mirror features of occupations in the traditional asbestos-using industries. One in four deaths due to mesothelioma now occurs in construction and maintenance trades workers (HSE, 2006b). In addition, home decoration and improvements are now undertaken much more frequently than in past generations, thus exposing large numbers of tradesmen such as joiners, plumbers, painter/decorators and electricians to asbestos.

Both government and individuals may be relatively unconcerned about a disease that takes many years to present following exposure to the causal agent: the individuals because the risk is remote compared with more obvious hazards such as road traffic accidents and smoking, and possibly because the disease does not impact on the active workforce and is still relatively uncommon. Sadly, a disease that affects many more men than women may receive less medical and political attention, even in these post-feminist times.

Peto *et al* (1999) predict that mesothelioma in Europe will increase in incidence in the next two decades in spite of the campaign to ban asbestos. Even in the apparently enlightened developed world, politico-economic influences still put lives at risk: in 1998 a Canadian trade mission persuaded the British government to delay a total ban on UK asbestos imports for two years for purely commercial reasons. They argued that a total ban of white asbestos (chrysotile) should not be mandatory because it has some unique industrial applications and is much less carcinogenic than other forms of asbestos. There is a powerful pro-chrysotile lobby, funded by the asbestos industry, that seeks to protect asbestos mining, manufacture and usage (Kazan-Allen, 2003). Although theoretically it may be argued that chrysotile should not be banned because of its low carcinogenicity in comparison with the amosite group, usage would need to be very strictly controlled. In practice, however, there are major issues that make these conditions unlikely to be satisfied: the difficulty in guaranteeing pure chrysotile uncontaminated by tremolite (although challenged by the Canadian asbestos industry); the socio-economic and practical conditions in resource poor countries where manufacturing takes place; the commercial implications; and the poor record of hazard management by the asbestos industry.

A powerful critique of the Canadian asbestos mining industry also condemns industry-funded university researchers (Egilman *et al*, 2003). Recent evidence has confirmed that Wagner, previously regarded as one of the fathers of mesothelioma research based on his seminal paper in 1960, was paid an honorarium of \$SA 6000/month by the asbestos industry, (McCulloch, 2006), although there is no evidence that this influenced his work.

In resource poor countries, asbestos mining, manufacturing of asbestos materials and the use of asbestos in relatively inexpensive housing and industrial settings are widespread, for example in India and South Africa (Kazan-Allen, 2005a; Jacobs *et al*, 2005). Globalisation and the commercial interests of multi-national concerns perversely encourage investment in asbestos industries in poor countries, whilst at the same time creating major health hazards. Attempts to interfere with the asbestos industry in resource poor countries are compromised by the likelihood that the economic consequences would be disastrous without some other major employment initiative. This tension between health and profit-making industry is at the heart of the social medicine tradition.

Social medicine may be regarded as extending the boundaries of both public health and epidemiology in its emphasis on whole societies and the prime importance of the relationship of social, political and economic factors to ill-health. Initially, Public Health services followed a government line with the aim of ensuring a healthy (working) population and tended to divide societies into demographic groups according to criteria such as age, sex, ethnicity etc and then apply medical initiatives e.g. vaccination, screening for disease, treatment of disease outbreaks, to the relevant groups. Social medicine has examined whole populations or social institutions, with social rather than individual units of analysis, in an attempt to find social solutions for the societal factors that create or increase risks to health (Waitzkin, 2001). A review of a medical controversy in 1839 illustrates the polarised approaches: in considering whether or not starvation had caused deaths, the statistician, William Farr, considered that hunger was a major contributory factor in many deaths whereas the 'pioneering sanitary reformer' Edwin Chadwick, wanted to determine the diseases which had been the final events (Hamlin, 1995). However, the distinctions between these terms are diminishing, particularly within the 'new public health' movement (Ashton and Seymour, 1988) that encompasses a wider agenda, much of it reflecting areas previously included under social medicine (Holland, 1994). An illustration of this trend towards more engagement with societal issues in the 'new public health' is the formation of Public Health Observatories

in each health region that aim to integrate specific local public health needs into local service provision and medical education (Ashton, 2000b).

The research methods underpinning the disciplines of social medicine, epidemiology and public health may also differ to some extent. Traditionally, epidemiology and public health methods may have favoured statistical studies in the investigation of large groups. However there are no clear divisions between these areas and perhaps an increasing convergence in line with the 'new public health'. Social medicine methodology favours a multi-method approach as this enables multiple perspectives to contribute to an overall picture. This approach, often combining quantitative and qualitative methods, allows individual contributions to be married with group or population units of analysis, de-emphasises the biomedical contribution, and can reveal the societal complexities around illness located 'in the matrix of society' (Yin, 2003, Malterud, 2001).

This study follows the tradition of social medicine in emphasising the social context of illness, and in which the case study approach is appropriate. Although UK studies abound that relate illness to the wider social context, most do not refer specifically to the tradition of social medicine. Many of these are described as epidemiological or public health studies and it may be that the term 'social medicine' is no longer popular and has been replaced by 'the new public health' or 'social epidemiology' in the UK. Although there is one university department of social medicine in the UK, my experience of discussing social medicine with colleagues lead me to conclude that, as a specific discipline in its own right, social medicine is not widely understood (rather like palliative medicine).

Studies that fit the definition of social medicine as 'medicine in its social matrix' include much of the work around health inequalities and social disadvantage. Examples include the classic studies on risk factors for coronary heart disease (Morris, 1953), inequalities in health (Black Report, 1980), and the social causes of tuberculosis (Mosse and Tugendreich, 1913). General practice or community-based studies include 'Epidemiology in a country practice' (Pickles,

1939), Murray *et al*'s (2003a) study comparing dying from cancer in Scotland and Kenya, and a doctoral study on farmers' occupational health (Gerrard, 1995). Social medicine studies have contributed significantly to knowledge of mesothelioma in first identifying the occupational nature of the disease (Wagner *et al*, 1960); confirming asbestos as a cause of lung cancer (Doll, 1955); and illuminating the working conditions and health hazard perceptions of asbestos mine workers (Cappelletto and Merler, 2003).

In our pluralist society it is perhaps not surprising that singular explanations of ill-health are less acceptable now than interactions of multiple factors. Genetic advances and better understanding of social and environmental impacts on health have also improved our understanding of causation of diseases. Coupled with media accounts of work-related health scandals, such as deaths due to lung cancer from passive smoking in the entertainment industry (Bramley, 2004) and the drowning of 23 illegal Chinese immigrants employed as cockle-pickers in Morecambe Bay in 2004 (BBC News, 2005), there is now increasing public and professional understanding of health issues in their social context.

LaMontagne and Walker (2004) highlighted a previously unrecognised desire on the part of a community 'damaged' by asbestos for some form of reconciliation and social healing. They also revealed a demand for community involvement in future public health interventions concerning asbestos-related conditions, such as the use of mesothelioma marker proteins, for example, mesothelin. In a similar vein, the plan for a memorial to the victims of asbestos diseases related to the Clydebank shipyard was recently presented to a UK conference (McKendrick, 2006)

However, as mentioned earlier, there is undoubtedly an overlap in the disciplines and practices of social medicine and public health. There are many impressive examples of designated public health practitioners who have achieved health gain for their populations by adopting a social medicine approach. Morris, mentioned earlier, campaigned passionately for improved housing when he was Medical Officer for Health for Glasgow, and subsequently was responsible for the politically-challenging Black Report (1980) on health

inequalities in his position as Director of the Social Medicine Research Unit (Watts, 2000). The confusions around the various terms and their interrelationships are illustrated by his insightful paper explaining why epidemiology should expand beyond infectious diseases (Morris, 1975). The 'new public health' attempts to reinstate the importance of social factors in ill-health. Primary Care Trusts are charged with delivering health services that are appropriate for their local communities and, in order to do this, their public health strategy must take account of local social factors, although tensions are likely to arise between central and local priorities (Ashton and Seymour, 1988). However, Petersen and Lupton (1996: ix-xvi) argue that 'traditionally modernist, science-based approaches' continue to prevail.

There is considerable debate concerning the lack of an established theoretical base to social medicine. Waitzkin (2001) points out that apparent lack of theory may in fact not be atheoretical or antitheoretical but may mean that the theory is implicit. Thus it is common in the developed world for research in social medicine to be defined as following a tradition rather than as having a theoretical base. Waitzkin (2001) states that researchers in Latin America utilise a theoretical stance that absorbs principles from a wide range of existing theories: Marxism relating to social class and the importance of economic production and exploitation of the workforce; feminism with regard to the burden of women as major wage earners, often providing a cheap source of unskilled labour and also carrying traditional child and home responsibilities; social group ideology; work process theory; and postmodernism. Waitzkin (2001) also points out that even epidemiological models that examine disease in relation to multiple causal factors may not be sufficiently wide-ranging to include dynamic social factors.

The outbreak of Legionnaire's disease in 2002 in Barrow-in-Furness that caused 6 deaths and hospitalised 17 people serves to illustrate the differences between traditional public health medicine and social medicine (Barratt, 2002). The public health investigation of the outbreak identified the organism responsible for the illness and traced its source to an air conditioning unit in a community arts centre in the centre of town. The Barrow Borough Council

maintenance engineer, who allegedly had failed to carry out routine procedures, was pilloried in the press and civil compensation claims may prove very costly for the council. Publicity centred on the need for tighter controls on maintenance of air conditioning units (BBC News, 2005).

A social medicine perspective would want to investigate why today's society feels it necessary to 'condition' indoor air. This could include assessment of the factors that lead to reliance on, and unquestioning belief in, technology; the factors leading to air pollution; and the reasons for poor ventilation in modern buildings. Possible solutions from a social medicine perspective might include drastic and unpopular measures to seriously reduce motor transport, enhanced HSE powers to tackle industrial air pollution, and radical changes to the design of buildings to ensure adequate natural ventilation. Headlines such as 'Air conditioning kills' would be as unacceptable now as those that questioned the safety of asbestos in the 1950s.

Social medicine supporters have suffered for their work and principles because, by definition, there are major political, economic and commercial implications of this approach towards ill-health. In his paper on social medicine in Latin America, Waitzkin (2001) interviewed 24 leaders of social medicine and reported that 20 of these had experienced political repression that included 'torture, imprisonment in concentration camps, exile, exclusion from government jobs, loss of economic security and work stability, loss of professional prestige and restriction of political activity'. Kazan-Allen (2003), a leading campaigner against asbestos, criticises the asbestos industry for 'the use of legal and physical attacks on individuals and groups who are considered a threat'.

In 1984 there was a successful case against Alan Dalton, British author of 'Asbestos Killer Dust: a worker/community guide' (Dalton, 1979). Dr Robert Murray, former medical adviser to the TUC, sued Dalton regarding comments in the book that criticised his 'pro-industry views' and his failure to effectively monitor the asbestos manufacturing plant in Hebden Bridge when he was the responsible Factory Inspector. Damages of £500 were awarded against Dalton with costs of £30,000, almost ruining the British Society for Social Responsibility



that produced the book. In spite of this judgement, Dr Murray subsequently gave evidence as an expert witness for Turner and Newall in support of the use of asbestos (Tweeddale 2000:248-9).

Although trade unions have campaigned for better conditions for workers, there has been criticism that they were slow to act before the Asbestos Regulations (1968), due to awareness that jobs were potentially threatened and that employers were reluctant to accept any problems related to asbestos, the 'magic mineral'. Johnston and McIvor (2000:158-76) detail the development of the campaigning against asbestos of the Scottish Trades Unions, initiated by the insulation workers, and leading in the 1980s to the now prominent pressure group charity, Clydeside Action on Asbestos. Even now, the conflict between the need for employment against the risk of death due to occupational disease some decades in the future, continues in resource-poor countries. South African asbestos mine workers rioted when their jobs were threatened because of the real danger of starvation without employment (Kisting, 2006).

The anti-asbestos campaign can be regarded as a social movement. In 1991 the growing international awareness of the need to campaign effectively and globally, resulted in the formation of the International Ban Asbestos Network (Kazan-Allen, 2003). This federation of international anti-asbestos campaign groups represents a growing social movement that includes powerful lobbyists from medicine, law, workers support groups, academia, trades unions and politics (Kazan-Allen, 2000). Kazan-Allen (2003) describes the increasing tension between anti-asbestos campaigners and the pro-industry lobby in her article entitled 'The Asbestos War'. On the one hand, campaigners against asbestos are becoming more powerful and sophisticated and can engage the public with highly emotive arguments; on the other hand, the asbestos industry is fighting for survival in the face of a great reduction of opportunities for commercial gain in the developed world and is concentrating on securing its hold on income generation in resource poor countries. The World Social Forum Conference, Brazil 2003, described as an instrument for change, included a workshop on asbestos led by Brazilian campaigners. This conference called for a global ban on asbestos (Kazan-Allen, 2003).

In summary, the investigation of palliative care needs of patients with mesothelioma and their families has to include an understanding of the issues involved in the rise and decline of the asbestos industry and the social, economic and political situations prevalent through the 20<sup>th</sup> and early 21<sup>st</sup> centuries. This is essential in order to make sense of the illness from the perspectives of the patients and their families in the real world context of their individual experiences and to understand their unmet needs with regard to palliative care services.

The above account of the 'social matrix' around mesothelioma and healthcare services for patients and their families leads to a range of issues for investigation. The importance of the social context, the acknowledged severe disease burden, and the lack of curative or effective disease-modifying treatments, naturally lead to an approach to the investigation in the tradition of social medicine and with particular emphasis on the supportive and palliative care issues. These considerations give rise to the following questions that form the research objectives for this study of mesothelioma in Northern England:

- What is the experience of mesothelioma for patients and their families?
- What is the experience of mesothelioma for healthcare professionals and service providers?

The next chapter explains how these questions led to the design of the study entitled 'The experience of mesothelioma in Northern England'

# Chapter 2: Methods

## 2.1 Study design

Following on from the research questions, this chapter describes how the design of the study was determined, the underlying theoretical framework and the practicalities of the investigation. These considerations led to a mixed method, community-based, case study in four parts and conducted in three sites in northern England where asbestos was used in major industries. This section will describe how both qualitative and quantitative methods were selected in order to address the research questions by obtaining data from four sources: patients with mesothelioma; bereaved relatives of patients who had died with mesothelioma; healthcare professionals involved in the care of patients with mesothelioma and, fourthly, medical case notes of patients who had died due to mesothelioma. The study follows the tradition of social medicine, as described in the Introduction.

### *Choice of subject and outline of the study*

As a GP and medical director of a hospice in South Cumbria I had noted an increasing number of patients presenting with mesothelioma. Most of these patients had been exposed to asbestos while working in the shipyard and heavy engineering works in Barrow-in-Furness. Problems controlling symptoms in some of these patients prompted me to search the literature for information and to discover that little had been written specifically about palliation in this disease. Discussions with palliative medicine colleagues revealed that many of them regarded mesothelioma as 'difficult to palliate' and this was subsequently endorsed in the BTS Statement on Mesothelioma (2001). This key publication was designated as a statement rather than guidance due to lack of sufficient evidence.

Mesothelioma seemed to be a particularly appropriate and locally relevant subject for investigation, given that Barrow-in-Furness has the highest

standardised mortality rate (SMR<sup>8</sup>) for mesothelioma in men in England, 593 between 1981 and 2000 (HSE, 2005a). I specifically chose to study pleural mesothelioma, excluding peritoneal mesothelioma, as the latter has different clinical features and is much less common. The research proposal, to examine the experience of mesothelioma in Northern England from the perspectives of palliative and social medicine, was then developed and colleagues at the University of Sheffield offered to supervise a doctoral study. At that time, GPs were able to apply for up to twelve months sabbatical under the Extended Study Leave Scheme that provided funds for locum cover in the practice and an Educational Allowance. My application for twelve months' leave was successful and enabled me to set up the study and to accomplish the majority of the data collection whilst on study leave. A bid for research funding from the Scientific Foundation Board of the Royal College of General Practitioners was also successful.

The broad aim of the study was to obtain a comprehensive understanding of the experience of the disease, its impact, burden and provision of health services, as experienced by patients and their relatives. The study builds on work in other diseases, for example, breast cancer, in which an understanding from the patients' perspective has led to service improvements. I felt comfortable with this approach as it fitted in with family-centred general practice and also suited the holistic approach underpinning hospice and palliative care. In addition, GPs see individual patients in their family, social, geographical, environmental and occupational contexts and develop knowledge of the social history of their practice area. Holden (2004) describes this as the 'social geography' of general practice, formulated by each GP as a unique and privileged 'mental map' that underpins their expertise. Given these considerations, and the history of mesothelioma, it was clear that social context could not be ignored in a community-based study of mesothelioma. Family members also needed to be included in acknowledgement of their vital role and the increasing recognition that carers of people with terminal illness have specific needs. (Payne and Ellis-Hill, 2001; Nolan, 2001a; Rose, 1997; Harding and Higginson, 2003; Department of Health, 2006b)..

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<sup>8</sup> The SMR is a measure of relative mortality: the ratio of observed number of deaths to expected number of deaths multiplied by 100. The SMR of the standard population is 100.

## *Choice of method and theoretical background*

In Chapter 1 the historical, industrial, and social context surrounding mesothelioma was described alongside the complexities concerning the disease and its investigation, treatment and compensation. Palliative care, like general practice, or family medicine, considers patients' problems as multi-dimensional: interlinking physical, psychological, social, emotional and spiritual domains (Box 1.3, p35). Consideration of the context around mesothelioma led to the conclusion that the study would follow the tradition of social medicine, defined as medicine in its social context and described earlier (section 1.7)

Social scientists, including researchers in social medicine, have increasingly favoured research methods that rely on multiple sources of evidence and many studies incorporate both quantitative and qualitative methods in case studies (Yin, 1994:1-8). This supported my choice of the case study approach, in which four data sources from each of the three sites were sampled. Yin (1994: 38-52) describes the careful consideration that needs to be given to the definition of the case in order to ensure clarification of the limits of the study and to determine the method/s of investigation. The overarching case was defined as 'The experience of mesothelioma in Northern England'. Table 2.1 demonstrates the relationship between the subsets in this embedded case study; the units of analysis; and the chosen research methods; as explained in the next section.

<b>The sub-sets</b>	<b>The units of analysis</b>	<b>The research method</b>
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

**Table 2.1: The design of the case study**

### *The case study approach*

Expert views of case study define it as either a research strategy or method. Yin (1981) defines case study as ‘a strategy for doing research which involves an empirical investigation of a particular contemporary phenomenon within its real life context using multiple sources of evidence’. Similarly, Robson, (2002:179), summarises the case study approach as essentially a research strategy that is empirical, studies a specific case, and focuses on the phenomenon in context, using multiple methods of evidence or data collection. However Bowling, (1997:359), defines case study as a ‘research method that focuses on the circumstances, dynamics and complexity of a case or a small number of cases.’

There are several essential components to the case study approach:

1. Case studies allow for investigation of a subject when context is an important factor. They reflect ‘lived world’ complexities in which ill-health has many interrelated factors such as social, economic and political situations (Yin, 1994:13). This mirrors the social medicine approach to this study in which an

understanding of the social factors behind the asbestos industry; the history of mesothelioma; and its status as an industrial disease; is crucial to understanding the experiences of patients and their families.

2. Case studies allow multiple methods and multiple sources of evidence to be incorporated thus obtaining more than one perspective. I wanted to extend beyond Barrow (although it would have been much simpler to undertake on one site) because this related to an outdated industrial situation unlikely to be repeated in the future. The same reservation applied to Leeds where the asbestos factory closed in 1955 but less so to Doncaster with its continuing power stations and railway works, albeit now governed by Health and Safety regulations. An additional practical consideration was the likelihood that few patients with mesothelioma would be available for interview in any one site within the study period. The use of three sites reflected at least four different industrial exposures to asbestos but also, by virtue of their relative regional importance, reflected differing levels of health service provision for cancer patients in the 3 sites, Table 2.2. Incorporating data from several sources allows for convergence of multiple data in the process of triangulation.

3. Case studies allow for early or prior hypotheses that may influence the study design. Given my interest in mesothelioma, it was inevitable that I would come to this study with some prior, if naïve, ideas about the subject. Prime amongst these was the impression that patients with mesothelioma had particular palliative care needs that were neither researched nor documented and that a deeper knowledge of these could lead to better care. There was little specific to palliative care in mesothelioma to inform the study in the literature apart from recognition that pain and breathlessness may be difficult to alleviate (BTS, 2001). Mercadante *et al*, (2000), reported a unique situation regarding mesothelioma in which opioid doses increase throughout the illness in contrast to other malignancies in which the trend is for analgesic doses to stabilise, (although only four patients with mesothelioma were included in a total sample of 434 patients with cancer). I also felt that the relatives of people with mesothelioma often seemed almost overwhelmed with the responsibilities of caring, and were severely affected by bereavement.

Cancer patients in general, and lung cancer patients in particular, as well as their family carers, have unmet needs concerning information and psychosocial support (Thomas *et al*, 2001:128-9; Krishnasamy and Wilkie, 2001:78-91; Department of Health, 2000b). Hill *et al* (2003) revealed that, after concerns relating to their illness, patients with lung cancer were worried about the impact of their disease on their close family. From experience, I considered close relatives of patients with mesothelioma to have specific needs regarding information and bereavement support but this had not been reported in the literature. The rival theory, as described by Yin (1993:149), would be that they had no specific palliative care needs compared with the nearest clinical group, that is, patients with lung cancer. However, I had no way of knowing whether or not my early notions would be confirmed by the study.

4. Case study design is flexible and there is no mandatory unit of analysis. In this study three of the four subsets, patients, families and healthcare professionals represent three social groups; each group contains multiple units of analysis that contribute to the overarching case: 'The experience of mesothelioma in Northern England'. Flexibility also applies to the ability to refine the study as data collection and analysis proceeds and to 'learn on the job' (Robson, 2002:182). This is how the first three interviews with patients in Barrow were conducted as a small pilot study, used both to test the feasibility of the method and as a trial run for me as an inexperienced researcher. Yin (1994:74) calls this a pre-test rather than a pilot, unusually Yin regards a pilot as an experiment to trial different methods of data collection. Alternatively, 'dress rehearsal', as in this study when the first three interviews informed the main study, is 'perhaps closer to the usual meaning of a pilot study' (Robson, 2002: 185).



	<b>Barrow</b>	<b>Leeds</b>	<b>Doncaster</b>
Hospital service <sup>9</sup>	District general hospital, cancer unit	Regional cancer centre across 3 hospitals in the city	District general hospital, cancer unit
Cancer services	Weekly clinic by visiting Clinical oncologist	Full provision in Leeds	Visiting oncologists
Radiotherapy	At Preston, ~70 miles from Barrow	Full provision in Leeds “	In Leeds or Sheffield, ~28 and ~17 miles away
Chemotherapy	Limited chemotherapy on site, most in Manchester, ~100 miles away	Full provision in Leeds “	Limited chemotherapy on site, some in Sheffield.
Cardio-thoracic surgery	In Blackpool, ~80 miles away	Full provision in Leeds “	In Leeds or Sheffield, ~28 and ~17miles away
Palliative medicine	1 consultant	5 consultants	1 vacant consultant post
Hospice	1 8-bedded hospice, 8 miles from Barrow	2 hospices across the city – 32 and 18 beds	1 hospice on the city outskirts, 10 beds

**Table 2.2: Hospital services for cancer patients in the 3 sites**

### *Why an embedded case study?*

The overarching case, ‘The experience of mesothelioma in Northern England’, may be viewed as a ‘conceptual umbrella’ that covers the multiple sub-sets or sub-units embedded in the study (Yin, 1994: 41). The aim of understanding the meaning and experience of mesothelioma from the perspectives of patients and their families could have been approached by joint or separate methods. I discounted the idea of trying to study patient/family carer dyads because I believed that recruitment of current carers would be extremely difficult given both the small numbers and the demands of caring. I had concluded that

<sup>9</sup> The NHS Cancer Plan (2000) defined 3 levels of cancer services: cancer units, cancer centres and regional cancer centres

investigating patients and bereaved family carers separately would be more feasible. In addition, in the absence of literature around palliation in mesothelioma, I felt it necessary to undertake a survey of the medical records of a number of patients with mesothelioma in order to underpin the data from patients and relatives with knowledge of the disease trajectory and the medical care provided in each of the three sites. A second reason for studying the medical records was to familiarise myself with the healthcare services in Leeds and Doncaster<sup>10</sup>; I only knew one healthcare professional in each of these sites prior to the study. In order to obtain a rounded picture of healthcare related to mesothelioma in the three locations I felt that the views of healthcare professionals should also be included. At the outset I intended that all the data sources would have equal weight. The inclusion of four separate data sources permitted triangulation of data or ‘converging lines of enquiry’ with the intention of improving research rigour.

The decisions around determining the type of case study were complex because there were several possibilities as shown in Table 2.3 below.

	<b>Single case designs</b>	<b>Multiple case designs</b>
Holistic (single unit of analysis)	Type 1	Type 3
Embedded (multiple units of analysis)	Type 2	Type 4

**Table 2.3: Basic types of designs for case studies** (Source: COSMOS Corporation, in Yin, 1994: 39)

Difficulties arose around deciding if the study was a multiple case study encompassing three separate cases relating to the three sites or relating to the four data sources or alternatively, whether it was more appropriate to regard the study as an embedded case study: an exploration of the experience of mesothelioma in which data from medical records, patients, bereaved relatives and healthcare professionals were not regarded as separate cases but rather as four embedded subsets that contributed to the overall case. My original intention had been to investigate on three sites for mainly practical (recruiting)

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<sup>10</sup> I was very familiar with the services in Barrow-in-Furness having been a GP in the area for 25 years

reasons (p 67) and I had assumed that there would be more similarities than differences concerning the experience of mesothelioma in these locations; any differences were predicted to relate to geographical location and distance from specialist centres as well as local level of health service provision.

A multiple case study that regarded the three locations as three separate cases would usually imply a comparative study and this was not the intention. If I had wanted a comparative study I would have chosen a more quantitative approach and paid more attention to 'sampling logic' (Yin, 1994: 45). The other type of multiple case study that I contemplated for this investigation was to consider the four data sources, medical records, patients, bereaved relatives and healthcare professionals as four separate cases rather than as embedded subunits. Again this might imply a more comparative study and both methods and analysis would have been approached in a different way, but in my study *understanding* rather than comparison was the main intention. In addition, although the distinctions are not absolute, I felt that, according to Yin (1994:45-7), if four separate cases had been chosen I should have sought more diversity amongst the samples: although the data sources were all drawn from the three sites they were each a fairly similar group, for example, with regard to the interviews with patients, most had worked in the 'traditional' asbestos-using industries. Thus the embedded design, with its emphasis on the overall case, seemed to fit more closely with both my original approach to this study and also with the tradition of social medicine, in which the overall experience of mesothelioma was to be explored in all its overlapping medical and social contexts and not to be seen as four separate investigations. To put it another way, patients and their relatives experience illness, not in isolation, but in their family, healthcare and wider social settings and this was reflected in the design of the study.

### *Definition of the sub-sets in the embedded case study*

Table 2.1 (p 61) illustrates the relationship between the components of the case study, the units of analysis and the chosen research method for each subset. As shown, there are 80 medical records as individual units of analysis within a subset, 15 individual patients as separate units of analysis within another subset, 6 focus groups containing 17 bereaved relatives within a third subset,

and 11 healthcare professionals as individual units of analysis within a fourth subset; these are all embedded in the overall case study.

### *Choice of three sites*

I realised at the outset that the study would need to be on more than one site in order to recruit sufficient patients and relatives due to the small numbers presenting with the disease in Barrow-in-Furness, approximately 12 per annum at the beginning of the study, and knowing that recruitment to studies in palliative care is difficult (Dean and McClement, 2002; Addington-Hall, 2002). I wanted to find other sites that would increase recruitment and that related to industries other than shipbuilding in order to increase generalisability, or, perhaps more accurately, transferability.

Practical considerations in choosing the sites related to my home being near Barrow and my doctorate being conducted at the University of Sheffield: as a lone researcher I felt that I could manage two additional sites provided that they were within reasonable distance of Sheffield where I could arrange accommodation during the period of study leave. I already knew of the mesothelioma cases in Leeds from the notorious asbestos textile factory in Armley and then discovered that Doncaster had the highest incidence of mesothelioma in men in Trent, apparently related to the large railway construction and maintenance plant. Leeds and Doncaster then became the two other sites, and were fortunately close to Sheffield. Apart from relating to differing industries with regard to asbestos exposure, the three sites also varied in the level of healthcare provision for patients with cancer (Table 2.2). Entwistle *et al* (2002) illuminate some of the interactions between practical considerations and methodology in studies of experiences of cancer.

*Barrow-in-Furness* is a declining industrial town in South Cumbria, population ~72000 in 2001<sup>11</sup>. It was built around the development of a shipyard that began in the late 19<sup>th</sup> century and many of the initial workers were impoverished migrant labourers from Ireland. The shipyard, and subsequently the neighbouring heavy engineering works, expanded during the Second World

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<sup>11</sup> All population figures are from the Census 2001

War to produce many famous warships and armaments. These were the major source of employment in the war years and later, until production declined in the 1980s, and were owned by Vickers Shipyard and Engineering Ltd. Asbestos was used extensively in both industries, mainly as insulation and fireproofing during manufacture and maintenance.

Barrow has a district general hospital, the nearest cardiothoracic centre is in Blackpool, ~ 80 miles away, and radiotherapy services are based in Preston, ~ 70 miles from Barrow. Some chemotherapy is provided in Barrow, but patients in clinical trials usually receive their treatment in regional cancer centres such as Manchester, 100 miles away.

*Leeds* is a large and wealthy industrial city in Yorkshire, population ~715000 in 2001. The main asbestos industry, until its closure in 1955, was the Roberts asbestos textile factory in Armley. This factory was responsible for heavy asbestos dust contamination of the surrounding residential area in one of the poorer districts of the city. The factory was next door to a school, former schoolchildren recall playing with the asbestos debris in the form of 'snowballs'. One of these, June Hancock, succeeded in a test case that established causation due to environmental exposure to asbestos (Budgen and Lipsitz, 2006:436-7). Leeds was also a suitable site because of its status as a regional centre for cancer services; all specialist cancer services are available in Leeds, although spread across the city on several sites. In addition, the Mesothelioma Information Service, a telephone advice service funded by Macmillan Cancer Relief, was situated in hospital premises in a Leeds suburb<sup>12</sup>.

*Doncaster* is a smaller city in South Yorkshire, population ~287000 in 2001. Doncaster was chosen for the study because it has the highest incidence of mesothelioma in Trent (Haselton, 2001). The main asbestos-using industry was a large railway maintenance and repair plant; however, on commencing data collection, I realised that the area has numerous power stations sited along the River Trent, and these subsequently proved to be linked to some of the cases of mesothelioma investigated in the study. Doncaster represents a midway

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<sup>12</sup> See description of the Mesothelioma Information Service in Chapter 6, section 6.7.

position concerning cancer services compared to Barrow and Leeds: although like Barrow it has a district general hospital, tertiary services are nearby in Sheffield or Leeds.

Initially, West Dunbartonshire in Scotland was considered as a study site because it has the highest incidence of mesothelioma in men in the UK: SMR 637, 1981-2000 (HSE, 2005a). However there would have been practical difficulties such as travel and accommodation as well as my unfamiliarity with Scottish health services as distinct from English services. A significant other concern was my anticipated difficulty in understanding the strong Clydeside accent during interviews (as experienced at a Clydeside conference).

### 2.1.1 Choice of methods used in the case study

In this section I explain the rationale behind the choice of the methods, Table 2.4. In order to produce credible results, the methods incorporated in a multiple methods case study must be selected to be the most appropriate for the research questions.

Research question	Methods
1.To investigate the experience of mesothelioma for patients and their relatives	1. a) Semi-structured interviews with patients b) Focus groups with bereaved relatives
2.To investigate the experience of mesothelioma for healthcare professionals and service providers	2. a) Review of medical records of deceased mesothelioma patients b) Interviews with health professionals

**Table 2.4: The relationship between research questions and methods**

#### *Medical records survey*

A survey of archival documents is designed to gather recorded data and to produce, in this case, a large database suitable for quantitative analysis. I decided to undertake a survey of the medical records of a number of patients who had died due to mesothelioma in order to gain insight into the local healthcare organisations, the disease trajectory and burden, and health

services provided. In order to obtain a comprehensive picture from the written records I decided to review GP, hospital, and where applicable, hospice records for each deceased patient studied. In Leeds and Doncaster, where I had almost no prior knowledge of the local healthcare professionals or organisations, this enquiry was also intended to familiarise me with the local healthcare contexts.

A proforma (Appendix 12) was used to standardise the data collection. This was amended by the addition of the following three questions after the first three records had been examined: other clinical investigations, place of death, and mode of death; this additional data from the first three records was then retrieved. The mode of death was often not recorded in the medical notes but could be found in the nursing records. As I felt that this was important information I decided to record the data regardless of its source. All other data was obtained from the medical records. This was for three reasons: firstly I am familiar with the format of medical records, secondly, I am unfamiliar with the format of nursing records and thirdly, the additional volume of data from nursing records would be overwhelming without guaranteeing any additional value in terms of data for this study.

### *Semi-structured interviews with patients.*

I chose to interview patients diagnosed as having mesothelioma in order to best explore their 'lived world' experience and meaning. In interviews, the task of the researcher is to make sense of what is said, and how it is said, by paying intense attention to the narrative and also to non-verbal communication. Interview accounts reflect the way in which people tell and retell significant life stories and can be viewed as a resource in which narratives may be a potent way of developing meaning. Interviews with patients may have a therapeutic effect in helping to 'contain' distressing issues. In addition, the account may be a way of framing the illness from the patient's or couple's perspective or alternatively, retelling may gradually produce an agreed 'public' account. Research interviews may have moral value as they may be seen as potentially helping future patients, indeed they may be regarded as a way of making a new and positive contribution by patients who are facing death.

I decided to conduct semi-structured or guided rather than open interviews in an attempt to focus on the main issues and to avoid over-lengthy sessions for people who may be very ill, short of breath or in pain. As a GP and hospice doctor, my working life revolves around listening to patients and their relatives and this had an affinity with the interview method which relies on the development of a relationship between the researcher and the interviewee. An interview guide was used (Appendix 4) in order to ensure that key areas were covered.

### *Focus groups with bereaved relatives*

Focus groups are recognised as being appropriate for the investigation of sensitive topics (Renzetti and Lee, 1993:166-176; Bowling, 1997:352-7). As mentioned earlier, I chose to involve *bereaved* relatives because I anticipated that the demands of caring for someone with a short and demanding illness, such as mesothelioma, would make recruitment of *current* carers extremely difficult. People may feel there is 'safety in numbers', particularly when the participants may be a traumatised or stigmatised group. Focus group members may act as prompts for others as they may have shared experiences. The experience of meeting others with much in common may reduce emotional distress, although there is the risk that the opposite could occur. There are varying opinions regarding the accuracy of relatives' accounts as proxies for patients, particularly with regard to symptom severity (Lobchuk and Degner, 2002; Addington-Hall and McPherson, 2001), although in this study it was primarily the experiences of the relatives that were being explored in the focus groups. There are ethical issues to consider in working with bereaved relatives such as concerns about 'raking it up again' and exacerbating grief; there may also be the risk of focussing on the negative aspects of the experience. However, the participants in this study were all volunteers.

Morgan (1988) describes 5 uses of focus groups: 'to orientate the researcher in a new field; to generate hypotheses based on informants' insights; to evaluate different research sites or populations; to develop interview schedules and questionnaires; and to get participants' interpretations of results.' In this study, focus groups were chosen primarily as data sources in order to develop



understanding and theory and, to a lesser extent, to enable cross-site and cross-method comparisons as described later, p82-4.

### *Semi-structured interviews with healthcare professionals*

Interviews were again chosen in order to illuminate the real world experiences of participants. Semi-structured rather than open-ended interviews were chosen in consideration of the time demands on professionals and an interview guide (Appendix 11) was used to focus the enquiry. As the professionals were from my peer group I believed it would be possible for me to delve deeper in response to prompts and examine variance between the participants. Edwards (1993), writing about feminist research, describes the value of 'double subjectivity' in research interviews in which the researcher is seen as a variable in the interactive process of interviewing; she relates this to non-hierarchical woman-to-woman interactions. Self-disclosure about my position as a GP/hospice doctor/researcher and my reasons for the study to healthcare participants who were my professional peers, alongside written information about the study prior to the interviews, established reciprocity in the interviews.

#### 2.1.2 Accounts of the methods in the 3 settings

##### *Sampling*

The size of the sample for each of the four methods was determined by a combination of research quality and practical issues, Table 2.5. The overall study is based on qualitative data supported by a quantitative survey. Statistical representation is not the intention, generalisability is the goal. Therefore the number of qualitative investigations needed to be sufficient to allow generalisability to patients and relatives in similar settings and also, importantly, a manageable number for me as a single researcher; the sample would therefore be opportunistic, depending on recruitment, and purposive. Although the original research proposal submitted for Local Research Ethics Committee (LREC) approval proposed up to 12 interviews in each of the three sites, this number was not achieved due to recruitment difficulties. In the end however, I was satisfied that the total of 15 interviews with patients provided rich data and fulfilled the need for transferability.

The size of the focus groups was limited by recruitment and they were again smaller numbers than I had originally envisaged. Several consented participants failed to attend on the day, leaving just one person for one 'group' in Doncaster, as discussed later, p96. However, considering the rich data that the groups produced, I was not disappointed with the outcome.

The choice of healthcare professionals to interview was determined by my wish to include the views of a range of professionals that could reveal the main issues around services for patients with mesothelioma. This was again an opportunistic and purposive sample that depended on availability at the time of the study.

The number of medical records sampled was also decided pragmatically, in terms of what I thought I could reasonably manage, plus consideration that a period in Barrow, somewhat arbitrarily chosen as three years, would produce a reasonably-sized sample that could be replicated in the other two sites. The sample size was not based on statistical power calculations because the intention was not to produce a statistically rigorous comparison across the three sites but to allow the findings to be reported in terms of descriptive statistics. It was intended that this would enrich the understanding of the disease trajectory and healthcare services concerning mesothelioma in the three locations.

	<b>Barrow</b>	<b>Leeds</b>	<b>Doncaster</b>
<b>Patient interviews</b>	7	5	3
Venues	Home 6, hospice 1	Home 5	Home 3
<b>Bereaved relatives focus groups</b>	2 groups 7 participants in total	2 groups 5 participants in total	2 groups 5 participants in total
Venues	1) Hospital conference room, Barrow-in-Furness 2) Arts Centre, Barrow-in-Furness	1) Solicitors office, Leeds 2) Solicitors office, Leeds	1) Community Centre, Doncaster 2) Hospice, Doncaster
<b>Healthcare Professionals</b>	4	4	3
Designation	Respiratory consultant, Specialist lung nurse, GP, oncologist	Specialist lung nurse, Mesothelioma help-line nurse, respiratory ward sister, cardio-thoracic surgeon	Specialist lung nurse, Palliative medicine consultant, Respiratory physician
<b>Hospital records</b>	26	27	27
Venues	Furness General Hospital, Barrow-in-Furness	Leeds General Infirmary, St James's Hospital, Cookridge Hospital.	Doncaster Royal Infirmary
<b>GP records</b>	26	27	27
Venues	Morecambe Bay Health Authority HQ, Kendal, Cumbria	E. Yorkshire Agency, Leeds	PCT HQ, Doncaster
<b>Hospice records</b>	5	13	9
Venues	Hospice of St Mary of Furness, Ulverston, Cumbria	St Gemma's Hospice, Leeds Wheatfields Hospice, Leeds, Yorkshire	St John's Hospice, Doncaster, Yorkshire

**Table 2.5: Details of the samples and data collection sites**

Conducting the study in my own locality, Barrow-in-Furness, was easier in every respect than in the other two sites. Familiarity with the Barrow healthcare professionals and organisations made communication and collaboration easy. In Leeds, as described later in the Ethics section, 2.1.3, the consultant in respiratory medicine invited me to give a presentation about the study to the hospital Lung Cancer Research meeting. This presentation led to support from the lung team for the study and two nurses who had been present subsequently participated in the study. In Doncaster, knowing the consultant in palliative medicine prior to the study was helpful in setting up a meeting with the team of Clinical Nurse Specialists, who then assisted with recruitment; two of them were interviewed for the study.

I began the data collection in Barrow for convenience and also because Local Research Ethics Committee (LREC) approval was granted there first. This allowed me to use experience in Barrow to effectively produce a template for the other two sites. In order to familiarise myself with each healthcare setting, I decided to undertake the review of medical records in each site before conducting interviews or focus groups. I also left the interviews with healthcare professionals until last in order to avoid reinforcing a 'medicalised' perspective that could cause bias in the interviews with patients and focus groups.

### *Conducting the medical records review*

#### Barrow-in-Furness

Once LREC approval had been granted for the Barrow study, copies of the letter from the LREC were sent to the Chief Executive and Medical Records Managers of the hospitals and primary care trusts and to the Chief Executive of the hospice where I am the Medical Director requesting access to the records of deceased patients who had died with mesothelioma between 1.1.1998 and 1.1.2001. Permission was readily obtained from all three sources. The details of 36 patients who died due to mesothelioma, that is, those in whom mesothelioma was included in Part 1a or 1b of the death certificate, within the 3-year period, were supplied on password-protected disk from the public health information department. The sampling frame, resulting in a final sample of 26 records, is shown in Figure 2.1. Access was agreed with the provision that the notes were to be examined on official premises: the hospital notes were examined over 5 days in the medical records department, the GP records were examined in the PCT headquarters over 4 days and the hospice notes were examined over 2 days in the hospice by the researcher.

Data collected onto a proforma, (Appendix 12) were subsequently transferred onto a computer software programme, Statistical Software for Social Sciences (SPSS), to assist with data handling and analysis. I decided to colour code the written proforma entries according to the data source, thus hospital data was entered in black, GP data in blue and hospice data in green. This was partly so that I could see where information came from but also to potentially be of use

for future research. The data collection and entry procedures were identical across the three sites.

### Leeds

As there were considerably more patients identified than in Barrow, 28 were randomised by the West Yorkshire Central Services Agency, aiming to achieve the same number as obtained relating to the same time period as in Barrow, see Figure 2.1. Details of LREC approval were then sent to the hospital and primary care trust chief executives and medical records managers with the list of hospital and GP records required. Once those patients who had accessed hospices had been identified, similar letters, relating to these patients, were sent to the medical directors of the two Leeds hospices. The hospital notes were spread across 4 hospital sites and were examined over 8 days. The GP notes were made available for examination at the East Yorkshire Agency and were examined over 5 days. Hospice notes were examined on site.

### Doncaster

Once LREC approval had been obtained, the letter of confirmation was sent to the manager of the medical records department. They provided details of the deceased patients and the total number over the 3-year period was similar to Barrow, see Figure 2.1. Hospital records were examined in the medical records department, GP records in the PCT headquarters and hospice records, after obtaining permission from the medical director as in Leeds, were examined in the hospice.

**Barrow :**

36 patients identified by Public Health Department from death certificate data

Less 1 patient because notes not traced

= 35 notes retrieved

Less 6 patients treated in Lancaster not Barrow

= 29 patients

1 admitted in extremis, not diagnosed or treated, post mortem diagnosis

= 28 patients

On detailed examination, peritoneal not pleural mesothelioma in 2, excluded

= 26 final sample

**Leeds:**

Names of 28 (same number as original Barrow sample) randomised deceased patients were supplied by the W Yorkshire Central Services Agency

7 records not traced by MDT co-ordinator, (records kept on 3 sites) locations)

=21 retrieved

A further 7 names randomised from remaining total and all retrieved

= 28

Less 1 patient who had peritoneal not pleural mesothelioma

= 27 final sample

**Doncaster:**

Trent Cancer Registry identified a total 30 deceased patients, 1 not traced

= 29 notes retrieved

Less 2 with other diagnoses – 1 adenocarcinoma lung, 1 had peritoneal not pleural mesothelioma

= 27 final sample

**Figure 2.1: Sampling frame for hospital records**

## ***Conducting the interviews with patients***

In all three locations, recruitment of patients was via clinical nurse specialists already known to them, either Macmillan nurses or Lung cancer clinical nurse specialists. The main entry criterion was that the patient knew and understood the diagnosis of mesothelioma. I met all the nurses personally to explain the study and to give them information leaflets, consent forms and stamped addressed return envelopes. An information leaflet (Appendix 1) was provided with the consent form. I always rechecked that consent was still valid at the start of each interview and offered to stop the tape if anyone became upset during the interview. The interview guide was a list of prompts that covered the various aspects of the patient's work and family background; disease onset; investigations and treatments; how the diagnosis was disclosed; the reaction to the diagnosis and then led onto current situation and, if appropriate, forward plans. The method, including the use of the interview guide, was reviewed after the first three interviews. I decided to use the first three interviews as a small pilot or in Yin's (1994:74) terms, a 'pretest', and as a result three items were added to the proforma: other investigations; mode of death; and place of death. These three interviews were included in the data for analysis as they did not differ substantially from the subsequent interviews. The 'working title' for these interviews was 'Palliative care in mesothelioma: What are the needs of patients and their families'; the final title arose once data collection commenced and it became apparent that the original did not reflect the scope of the study<sup>13</sup>.

My hospice catchment area included Barrow; therefore I was careful to avoid introducing the study personally<sup>14</sup> to any of the patients with mesothelioma for whom I was responsible. Recruitment was slow and erratic because, although Barrow has the highest SMR for mesothelioma in men in England, at the time of commencing the study that equated to around 12 cases per year.

With the exception of one Barrow interview that was conducted in a hospice, (at the patient's request, he was an inpatient at that time), all the interviews were conducted in the patients' homes. The spouses of all but one of those who were

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<sup>13</sup> As reflected in the study title in letters to patients etc found in Appendices 1-9 as this was the title used in applications to LRECs..

<sup>14</sup> The Macmillan nurses or lung cancer clinical nurse specialist recruited all the patients in Barrow

married were present (I had not mentioned this in the information leaflet). One cohabiting partner was in the house during the interview but in another room.

I was aware that the patients and/or their relatives may find the interview distressing and made every effort to handle the interviews with sensitivity. At the beginning of each interview I checked that consent was still valid and assured the patient that they could terminate the interview at any time without penalty or displeasure. The patient was invited to give a brief background of their family and then their occupational history. This naturally led to consideration of how they had been exposed to asbestos and whether or not they had been aware of the health hazards at any time during their working life. Once this had been clarified I asked the patient to describe the onset of their illness and/or how diagnosis had been reached, how it had been communicated and how they had reacted at the time. This was followed by enquiring about their current symptoms, effects on their normal life and, if the patient was willing to discuss it, their thoughts on looking ahead to advancing illness and dying. I followed the patient's lead with regard to discussing death; most avoided the issue but some were clearly willing to confront and talk about death openly. On several occasions patients did become emotional but, in every case, given time to regain composure, they wished to continue the interview.

The interviews lasted from 27 to 93 minutes apart from the contribution of one man that was just one word, '*devastated*', as described in Vignette 4.2, p162. At the end of the interviews I thanked the participants and asked them if they had any questions. I also checked that the patient had access to support from either a Macmillan nurse or other clinical nurse specialist. Not surprisingly, as this was how they had been recruited, they were all in touch with a specialist nurse. The mini disk recordings were then transcribed onto my laptop computer and entered onto a software programme, Atlas-ti for assistance with data-handling and analysis. The disks and transcripts were kept in a locked cabinet in my office.

### ***Conducting the focus groups***

Bereaved relatives for the focus groups were recruited either through clinical nurse specialists who had been involved in the care of the deceased patients or



via adverts or articles in the media (Appendix 5). An information leaflet was supplied and written consent obtained (Appendices 7 and 8). Only in one case was a focus group member related to a patient who was interviewed: Dora participated in a Barrow group 3 ½ months after the death of her husband (Mr I, Table 4.2) who was interviewed early in the study. In at least three cases recruitment was by word of mouth from people who had seen an advert or heard about the study on the radio.

After introductions, and before the group began, I assured participants that they could leave or stop the group at any stage without penalty. I asked the participants to give a brief summary of their involvement with someone who had died with mesothelioma. Participants were asked to try to follow the story of the person that they had cared for, from the onset of symptoms to death and bereavement, taking one stage at a time where possible to allow for group discussion. I used small group facilitation skills acquired in general practice education to manage the groups, ensuring that all participants were able to contribute and that no one person or issue dominated the sessions. A guide (Appendix 9) was used (lightly) to ensure that key areas were covered. Light refreshments were provided and £5.00 for expenses was given to all participants. The focus groups were recorded onto mini disk then transcribed and entered onto Atlas-ti software. A list of support organisations including bereavement services was provided at the end of the sessions.

Although I had planned for an assistant to be present during the focus groups in order to assist with practical details such as refreshments and recording, this did not happen: the proposed assistant for the first two groups was unexpectedly unavailable on those days. However these groups appeared to run well without an assistant and I then felt that an assistant might disturb the balance of the remaining groups, particularly as the numbers of participants were smaller than anticipated.

### ***Conducting the interviews with healthcare professionals***

Opportunistic, purposive, semi-structured interviews were conducted with a variety of healthcare professionals across the three sites. These were not designed to be representative, but to give a range of views and experiences

related to the management and care of people with mesothelioma and their relatives, as shown in Table 2.5. Recruitment was determined by availability and my knowledge of the doctors and nurses either personally or through the medical records review. A letter was sent confirming the agreed time and date of the interview and requesting a signature giving written consent to the interview. In each case I attempted to determine which professional in each field had considerable experience in mesothelioma. The interviews were all conducted in the normal workplaces of the professionals involved and took from 15 minutes to 55 minutes. An interview guide was used to ensure coverage of key areas (Appendix 11). The interviews were recorded, then transcribed and entered onto a software programme, Atlas-ti, to assist with data handling and analysis.

### *Analysis of qualitative and quantitative data*

Qualitative research interviews are premised on the conversation between the researcher and the participant, and 'words are their main currency' (Vallis and Tierney, 1999). Analysis depends upon the interpretation of the data (words) in the hermeneutical tradition: hermeneutics can be regarded as how we reach an understanding of the meaning of a text (or text analogue). As interpretation is inherently subjective, it is important that researchers' perspectives are articulated as these will shape the understanding of the data, as in the Introduction, p 58-9. (Byrne, 2001).

Interpretation of qualitative data in this case study was not limited to studying words in isolation. The process of interpretation was situated; for example, my observations of the setting, non-verbal communications between the participant and me and between the participant and their spouse, my field notes written following the interviews, and my prior (and developing) knowledge of mesothelioma, were all relevant to a growing understanding that ran alongside the process of data collection. Moreover this was an iterative inductive process in which developing notions were tested by feeding them into new interviews and focus groups or discussions with colleagues, essentially an informal process that accompanied the 'formal' analysis, but crucial to developing a deep understanding of the experience of mesothelioma.

The more formal analysis began with careful listening to the recordings of the interviews and focus groups several times before moving on to using the transcribed data that had been entered onto Atlas-ti software. This programme enables words or passages of text to be selected and then coded as determined by the researcher. All quotes assigned to a particular code may be retrieved simultaneously and codes may be easily grouped together as developing themes emerge. Atlas-ti has many sophisticated functions but I simply used it for data handling and coding. An alternative programme, NUD\*IST, was considered but I found Atlas-ti easier to use. I tried to avoid reductionist splitting of texts into isolated words and attempted to retain the *essence* of the accounts from the participants.

After reading each transcript several times, I began the process of highlighting each significant section on the computer, deciding how to code it and then entering it under the appropriate code or forming a new code. As the number of codes increased, I grouped related codes together as themes or categories, following the Miles and Huberman (1994) first- and second- level coding system. From these major themes, I was able to begin to develop ideas or early theories relating to the findings of the interviews and focus groups. This process follows the grounded theory approach of Glaser and Strauss (1967) as a means of managing data and depends upon analytic induction as a method of data analysis. Thirteen tactics for generating meaning have been described by Miles and Huberman (1994: 245-6), Box 2.1:

1. Noting patterns, themes and trends
2. Seeing plausibility
3. Clustering
4. Making metaphors
5. Counting
6. Making contrasts and comparisons
7. Partitioning variables
8. Subsuming particulars into the general
9. Factoring
10. Noting relations between variables
11. Finding intervening variables
12. Building a logical chain of evidence
13. Making conceptual/theoretical coherence

**Box 2.1: Tactics for generating meaning** (Miles and Huberman 1994:245-6)

Initially I analysed the data from the four subsets, (Table 2.1, p61), separately but then began to reflect on the findings and how they were related across the

subunits. Similar findings were brought together in what Miles and Huberman (1994:98) describe as 'pattern matching' (Box 2.1) and variances or conflicting findings were examined to see how they affected developing theories.

For example: Several codes related to the involvement of family members, usually wives, in the experience of mesothelioma, and these codes reflected a very strong bond within the married couples. Rereading the texts, recalling the behaviours of the couples during interviews, reviewing the focus group data, and rereading my field notes, all combined to confirm my impression of the couples coping together as an important theme. I then grouped these related codes under the category of 'in it together' – an example of triangulation of data from different sources and differing data collection methods. Later reflections, explored in the Discussion, Chapter 7, linked this category to the section on 'caring in the family' and to the emerging theme of 'the narrative of coping'.

It was apparent during the early phase of analysis that coding, categorising, and triangulation were parts of an iterative mental process. This happened concurrently alongside the more structured physical coding and categorising using the Atlas-ti programme; on occasions 'sparks' or 'flashes' of insight occurred (Robson, 1994:478).

Robson (1993:478) suggests that interim summaries are helpful in managing large quantities of qualitative data. Although I had not planned to do this, I found that requests for presentations of my work in progress starting in the first year of the study and increasing as awareness grew in 'mesothelioma circles', (Appendix 13), actually served this function: preparing presentations clarified my thoughts and imposed a necessary discipline.

*Quantitative* data from the review of medical records was entered onto the SPSS<sup>15</sup> software programme. The study was not designed to produce statistically valid findings in terms of significance, and recruitment was not based on power calculations: the quantitative data was intended to complement the qualitative data and to inform the findings. Descriptive statistics are a feature of the SPSS programme that allows findings to be presented as mean or median values, and enables the range of results to be

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<sup>15</sup> SPSS = Statistical Package for the Social Sciences.

readily obtained and to be presented graphically. Where there were marked differences between the three sites the results have been separated by location, but in most cases the results were aggregated because the study was not primarily meant to compare the three sites.

### *Funding*

An initial research proposal was submitted to the June Hancock fund, at the time this was the only fund specifically for research into mesothelioma in the UK. The proposal was given to a trustee of the fund, herself a research assistant working in the field of patients' concerns in lung cancer. The proposal was rejected, mainly on the grounds of being too large for a sole inexperienced researcher. Fortuitously for me the detailed written critique was included with the rejection letter. I amended the proposal in light of the critique and the next application, to the Scientific Foundation Board of the Royal College of General Practitioners, was successful. At the same time I successfully applied for twelve months Extended Study Leave from full-time General Practice, and I was also granted an education allowance and locum expenses. (Sadly this scheme has subsequently been absorbed into general funds)

#### 2.1.3 Ethical issues

There are concerns that interviewing people about sensitive subjects, for example about their way of coping with facing death, may cause harm to the patients; the ways in which I attempted to minimise harm to any participant is described later in the data collection section. However, invitation to contribute respects patient autonomy, and there is evidence that participating in a research project, even when there is no obvious gain for the patient, can be a positive experience in patients with terminal illness (Addington-Hall, 2002).

Involvement in research may lead patients to expect some personal gain from the undertaking. With one exception, I was not responsible for the clinical care of the patients or relatives in the study and I made it clear to participants that I was not, and could not be, involved in their treatment. I discussed the situation with the one participant who was my patient in the hospice and who was clearly

keen to participate in the study<sup>16</sup>. I assured him that his treatment would not be altered by his participation and he appeared to understand the situation and wanted to 'tell his story'.

In spite of trying to address all potential ethical issues I did not predict one potentially harmful outcome of a focus group: During a group discussion around prior knowledge of asbestos-related disease, a widow expressed concern that her son may have been exposed to asbestos on his father's work clothes. This conversation made another participant, a daughter of man who died with mesothelioma, suddenly realise that she may have been exposed to asbestos on her father's overalls. Realising that this needed to be addressed, I offered to discuss the issue with her after the group. In that discussion it appeared that her father had been a maintenance engineer for a food manufacturer and he believed that he had inhaled fibres from decaying asbestos lagging on pipes in the cellars of the factory. He did not appear to have had heavy constant exposure to the extent of visible contamination of his work clothes. Moreover he had worked all over the plant and not mainly in the cellars. In the circumstances it felt reasonable to give reassurance to his daughter that her exposure had probably been light. However, although on balance, reassurance was better than alarm when there was nothing this lady could have done to reduce her risks of developing mesothelioma at this stage, this reassurance left me uneasy. I could not quantify her risk, knew that there is no known safe exposure threshold and did not know the type of asbestos in the factory. This highlights tensions between my responsibility as the researcher; my knowledge of asbestos risk; the management of difficult and uncertain information; and my duty as a doctor to 'first do no harm', complicated by her (unknown to me) expectations of me, knowing that I am a doctor.

Advertising the study in media interviews, and advertisements for focus group participants, raised expectations in people who were not eligible for the study but, nevertheless, may have had unresolved bereavement issues. In spite of the eligibility criteria being clearly specified, several people bereaved due to mesothelioma, some many years ago, telephoned the secretary at the Trent Palliative Care Centre who had kindly agreed to take the calls. I phoned all

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<sup>16</sup> His wife recruited him to the study: she had heard about it from a Macmillan nurse without my knowledge. Significant treatment decisions did not arise related to this patient.

these callers to thank them for their interest and to explain the reasons why they were not eligible for the study. I did not get the impression that any of them were currently distressed but had intended to suggest that they contact their GP if they had appeared to be. In most cases they expressed appreciation that I was researching in this area and that this would hopefully lead to improvements in care of future patients.

### *Achieving LREC approval*

Applications for ethical approval were made to the Local Research Ethics Committees for the three sites. Each committee had its own application forms, ranging from 5 pages in Barrow to 13 in Leeds. Multiple copies of the application forms, maximum 17, had to be posted to each committee.

**Barrow:** The first application, submitted in July 2000, related to a small interview study of three patients with mesothelioma in Barrow and was originally intended as an assignment for the Qualitative Research Methods Module of the MA in Health Research Methods at Lancaster University. Approval was granted in August 2000. Recruitment was slower than expected due to attrition and my inexperience. I had to request two amendments to the original protocol in order to increase recruitment: firstly to extend the recruitment criterion from 'shipyard workers' to include 'people indirectly exposed to asbestos', and secondly to further extend the same criterion to 'three mesothelioma patients from the Barrow-in-Furness area.' As a result of slow recruitment the deadline for the assignment was exceeded, but in the meantime I learnt that my application for extended study leave had been successful. This then enabled the three interviews to constitute a pilot study for the interviews with patients. A further application for the complete case study was granted in July 2001 once two conditions had been satisfied: 1) that I amended the protocol to include either reimbursement of travel costs or a token payment (£5.00) towards costs to focus group participants, and 2) that the information leaflet for participants was amended accordingly.

**Leeds:** I applied in August 2001 and LREC approval in principle was granted immediately, on two conditions: 1) that a Leeds consultant should be the local co-investigator and 2) that I comment on the recruitment of focus group participants through newspaper advertisement. The committee were

concerned that, as a self-selected group, the sample would not be representative. A consultant in respiratory medicine with an interest in mesothelioma agreed to be co-investigator and I clarified that the sample was intended to be a purposive volunteer sample and not statistically representative. My co-investigator then sent the protocol and LREC letter confirming approval to the Leeds Health Authority Caldicott Guardian, (see next section), who also approved the study. Details of deceased mesothelioma patients were requested from the Northern and Yorkshire Cancer Registry and Information Service (NYCRIS) with copies of LREC and Caldicott Guardian approval but access to the records was not agreed until the study had been discussed at the NYCRIS Advisory Group in October 2001.

**Doncaster:** The Doncaster LREC replied to my initial application in August 2001 with an invitation to an early morning meeting to discuss three areas of concern: 1) 'it was felt that a quantitative study must provide (sic) sample size calculations and an end point', 2) 'whether enough information would be obtained from the 36 case studies' (referring to the original intention to recruit 12 patients for interview in each site), and 3) 'that as the study only looks at those referred for palliative care this could reflect a biased group'. This last point was a misinterpretation of the protocol. I submitted a written response to the three points prior to the meeting. At the meeting, concern was expressed by one member about the 'small' number of interviews proposed but the chairman reassured him that even smaller numbers were normal in this type of study. Another member was concerned about the use of statistics and did not want me to make comparisons between Doncaster and the other two sites – '*we don't want any 'iffy' statistics*'. I assured him that I had taken expert advice regarding the analysis of the quantitative data and that the findings would be reported in the form of descriptive statistics. Approval was confirmed a few days later on condition that I removed one of the original objectives: 'to develop recommendations concerning the provision of palliative and supportive care to mesothelioma patients and their families in Primary Care and community settings'. The letter also repeated the request that I should not compare the Doncaster findings with the other two sites; I presumed it reflected anxiety in case of perceived poor performance. Full approval was granted in November 2001 once I had agreed to these conditions.



### *Data protection legislation*

Confidentiality of personal data is governed by the Data Protection Act (1998) and details of compliance with the act were included in each application for LREC approval. In this study I endeavoured to protect the identity of participants in a variety of ways. The medical records that I surveyed were each given a unique numerical identifier that was used on the proforma and transferred to the SPSS database. The details of individual deceased patients and their accompanying identifier were kept in a locked filing cabinet in my office. In reporting the findings I did not reveal any individual's details that could be used to trace back to a specific patient. However I did decide that, with regard to the records survey, the three sites should be identified separately in the report because variations, particularly in health service provision, usually depended on external factors, such as health policy or geography, rather than the actions of single healthcare professionals; therefore I did not feel that any of the information should cause harm or disadvantage to any one professional or department. There was also the likelihood that, if I had not identified the data from each of the three sites separately, it would not have been difficult for local readers of the report to deduce where data originated due to the differences between the sites.

The details of the patients who were interviewed and the focus group participants were all amended in some way, such as alteration of their age and by assigning different initials, in order to make them difficult to identify by anyone other than close family members. It is inevitable however, that in some cases, for example when an extraordinary experience has been described, that there may be some compromise of confidentiality. I have tried to minimise this wherever possible but felt that the report did not include any instance where such compromise would disadvantage or harm the person concerned.

The details of healthcare professionals were protected by not revealing their location and by referring to them by job titles rather than by initials. Inevitably, some compromise is involved, in that certain details would enable a local reader to deduce the data source. However, I judged that the comments made in these circumstances would not disadvantage the interviewee. The one exception was the nurse who provided the Mesothelioma Information Service, a unique nationally-available service that was widely publicised and associated

with the name of the nurse concerned. Recognising that confidentiality was not possible I obtained specific written permission from the nurse to include the interview knowing that it would identify her, although I omitted her name from the report.

The post of Caldicott Guardian in each healthcare provider organisation was established in response to the Caldicott (1997) report relating to patient confidentiality. The Caldicott Guardian is responsible for the safe and legal handling of patient-identifiable data. Only in Leeds was my study submitted to the Caldicott Guardian of the hospital trust for approval.

## **2.2 Methodological issues**

### **2.2.1 Recruitment issues**

The study was limited due to the familiar problems of recruitment in palliative care studies and also because I was working alone and in two unfamiliar sites. Recruitment to any palliative care research project is known to be difficult and I was aware that it could be particularly problematic in mesothelioma as patients may present with very advanced disease (Addington-Hall, 2002; BTS, 2001). In addition, from my experience of caring for patients with mesothelioma I recognised that, alongside coping with medical investigations and interventions, patients may also be involved in time-consuming and stressful legal procedures and benefit claims which would possibly also reduce the chances of recruitment. Recruitment was slow and erratic: it took 8 months to recruit the first three patients in Barrow. Gate-keeping by clinical nurse specialists in palliative care was difficult to determine but 'clinician barriers' have been reported (Addington-Hall, 2002; Steinhauser *et al*, 2006). Another limiting factor was the busy investigation/treatment schedules that some patients were undergoing. One wife cancelled an interview that a patient had consented to in writing. When I telephoned to make an appointment the patient's wife said that he was reasonably well at that time and she did not want him to be interviewed because '*it might upset the apple cart*'. Although this left me wondering what the patient felt about the interview, I felt unable to ask to speak to the patient for fear of causing distress.

As a doctor myself, I predicted that access to healthcare professionals would not be restricted, and this was usually the case. However I was apprehensive about access in Leeds and Doncaster because I was unknown there and, as illustrated by other researchers, (Bergen and While, 2000), familiarity is known to facilitate access. I also worried that my identity as an unknown GP, unknown researcher, and from another area, may cause some concern to the participants in Leeds and Doncaster although these worries appeared to be unfounded.

### 2.2.2 Limitations of the case study approach

The case study as a research strategy attracts three main criticisms: lack of research rigour, lack of scientific generalisability and time-consuming studies that result in unwieldy reports (Yin, 1994: 9-11). These are addressed in the following 5 sections.

The broad scope of this multiple method case study entailed a large literature review across many fields and this increased the possibility of missing important publications. Fortunately 'alert' facilities provided by electronic databases remedy this to some extent with regard to major publications, although using 'mesothelioma' as a search term results in an avalanche of references to legal proceedings and union activities alongside medical papers.

*The case study* sampled patients and relatives from 3 areas with a high incidence of mesothelioma that, inevitably, related to traditional industries. Although Peto *et al* (1999) predict that the UK incidence of mesothelioma is likely to rise until around 2015, the demography and distribution of mesothelioma is already changing as manufacturing and heavy industry decline and this is not reflected in this study. The study did not investigate patients whose mesothelioma related to asbestos exposure when self-employed or when asbestos exposure did not relate to the traditional industries. However, although the exposure routes are changing, there is no evidence to suggest that the disease is any different however it is attributed, and therefore the palliative care needs should be the same. Two areas that may be different are: 1) compensation, which will be more difficult to prove away from the traditional industries, and 2) medical knowledge may be affected as the experience gained in high incidence areas is unlikely to apply generally. Given the resources and time limits of this project it would have been extremely difficult to recruit many

patients whose mesothelioma was unrelated to the ‘traditional’ asbestos-using industries, although in two or possibly three of the patients interviewed, bystander exposure was implicated.

The study was cross-sectional, not longitudinal, and therefore could not demonstrate changing needs along the disease trajectory. This may have been countered to some extent by recruiting patients at all stages of the disease and having different types of treatment, admittedly by chance rather than by design, including two people interviewed within a week of death.

Flexibility is a feature of case study design and in this study the significant alteration to the original proposal was the removal of a 5<sup>th</sup> component: I had hoped to include a national questionnaire survey of patients with mesothelioma to investigate disease burden and quality of life by using validated instruments. Fortunately caution prevailed, because this would have made the study unmanageable.

The findings do not reflect recent changes in healthcare services, such as: GPs are no longer responsible for out-of-hours cover; universal MDTs which were only developing at the start of the study; introduction of medical thoracoscopy; and slightly more promising results from chemotherapy trials. In addition, there has been a great increase in media coverage of mesothelioma as we head towards the peak of the mesothelioma epidemic in the next decade (Peto *et al*, 1999) and public awareness is likely to have increased. Medical education around mesothelioma has also grown with an ever-increasing number of conferences in the UK and abroad<sup>17</sup>.

Case studies may be criticised for a variety of reasons. They may be regarded as ‘not scientific’ on the grounds that their multiple methods and multiple data sources do not lend themselves to thorough analysis. However the case study approach mirrors the way in which people see the world, not just from a single perspective but from a multitude of angles and with many layers of information, and therefore it can be argued that case studies provide a more realistic method of exploring experiences and meaning. Secondly, it may be argued that case study results cannot be generalized. However this is a misunderstanding as

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<sup>17</sup> See Appendix 13 for a list of presentations related to this study

case studies are designed to test or develop theories, the cases are not selected to be representative, and the studies are not designed to answer specific limited questions (Yin, 1994: 37). Another criticism is that case studies often generate huge quantities of data and that this may lead to over-long reports.

Alderson (1998) argues that quantitative methods do not fit well in case studies whereas Yin (1994:92) accepts the consideration of all methods in case studies in order to provide multiple perspectives and methodological triangulation and he suggests that there is considerable overlap between qualitative and quantitative methods. There is a debate about the validity of multiple methods approach: criticisms of 'methodological pluralism' are, firstly, that there may be an implication that the results from the different data sources will be broadly similar, and secondly, that data sources may be variably weighted thus introducing bias. However, a more common view is that complex and/or contradictory findings reflect the 'messiness' of real life (Devine and Heath, 1999: 48-50).

Criticisms of mixed methods case studies are countered by rigorous attention to study design; transparency about prior hypotheses or notions and the theoretical underpinning of the study; transparency about data collection and analysis; and a clear account of conclusions and how they were derived. Yin (1994:33) demonstrates how the four basic tests of social science methods i.e. construct validity, internal and external validity and reliability can be satisfied by careful attention to 'case study tactics'. Several authors have produced guidelines for assessing the rigour of qualitative research that can be applied to case studies incorporating mixed methods (Mays and Pope, 1996: 18; British Sociological Association Medical Sociology Group, 1996; Spencer *et al*, 2003; Seale, 1999: 189-192). In the sections concerning the qualitative components of the case study I have attempted to address these issues.

Vallis and Tierney (1999) conducted a multiple site, multiple methods case study into the care of patients with hip fractures. In their account of the methodological issues in the study, they conclude that although '*complex case studies provide a powerful method for describing and explaining complex health services... the practical difficulties and methodological complexities should not*

*be underestimated.*' Similarly, Yin (1994:45) warns that such studies '*can require extensive resources and time beyond the single student or independent research investigator*'. Vallis and Tierney (1999) draw attention to the tensions in triangulating data from quantitative and qualitative methods given their different research traditions. However Sandelowski (1995) suggests moving from the two-dimensional model of triangulation to the more complex notion of a prism or crystal and attempting to reach an accommodation or 'peaceful coexistence' of multiple findings rather than convergence to a single point. This multidimensional concept captures the complexities of real life, and applies to this study that is designed to investigate the lived world experience and meaning of mesothelioma.

### *Limitations of the incorporated methods*

*The medical records survey* revealed the limitations and challenges of data collection from medical records that are well-known and include illegibility, incompleteness, disorganisation and problems with access and retrieval. These difficulties may often obscure the actual sequence of events and reasons for medical management decisions. These problems may be exacerbated if notes relating to deceased patients are given less status than notes of live patients and therefore not cared for adequately. Retrospective surveys of records rely on accuracy of the recorded data and it is not possible to validate or verify the recorded information. Survey methods are time-consuming and a particular issue in deciding to survey GP, hospital and hospice records involved accessing the records and collecting data in a variety of sites. A potential difficulty was access to the records in voluntary independent hospices, (three of the four involved), that are not governed by NHS regulations – in practice this was not a problem.

*Limitations of semi-structured interviews* include the following: selection bias: some people may not want to be interviewed, particularly concerning sensitive topics and this will skew the sample, that is, only those who are prepared to be interviewed will participate. Secondly, patients with mesothelioma may be too ill or busy with medical interventions to be interviewed; some patients may be too emotionally upset to engage in the extra burden of interviews; the proforma may skew the content of the interview; non-verbal communications may be missed;

the relationship between the researcher and the participant may impact on the process; and the quality of the data may be determined by the skill of the researcher. In addition it is likely that distressed or seriously ill patients may reasonably not wish to be interviewed.

As described by Edwards (1993) the 'sex, race, class and educational experiences of the researcher and the researched' can affect the degree of sensitivity of interviews into delicate areas. My medical status may have impacted on the interview process: on one hand people may have been prepared to discuss details of their illness with me in the expectation that I would understand and focus on the physical aspects of their situation; this could mean that more social or emotional aspects were suppressed. On the other hand, my professional background may have been a barrier to communication, in spite of my efforts to present as an interested researcher with 'professionalised friendliness' (Seale, 1999:20). However, in interviewing patients in their own homes, the researcher is an invited guest, and has no control over the environment, others present (including pets), distractions and timing<sup>18</sup> (see 2.2.3, p96).

In addition to the limitations of the interview method described with regard to patients, the interviews with healthcare professionals had other potential restrictions. Firstly, for most of the participants, interviews were fitted into the working day and so time was limited. Assumptions may have been made by both me and the interviewees due to our common healthcare work. Some degree of 'saving face' or reputation may be involved in circumstances when the enquiry may be perceived by the interviewee as potentially critical of services provided, leading to defensive responses or reluctance to discuss problem areas.

The *limitations of focus groups* include the potential dominance of more articulate or confident members, the difficulty of ensuring the discussion does not veer completely off course and the skill required in the group leader or facilitator to achieve a reasonable balance between focus and important areas not necessarily included on the guide. Focus groups exploring sensitive issues may be emotional and a negative experience for some participants – my

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<sup>18</sup> See Vignette 4.2, p162.

attention to minimising risks to the participants is described in the data collection section. Current carers were not included in this study, due to practical considerations, but it would have been more complete with their data. Bereaved carers are reporting 'through the lens of loss'; the participants were volunteers who were likely to have a 'story to tell' and these retrospective accounts are likely to differ from contemporaneous accounts (Higginson et al, 1994; Hinton, 1996; Addington-Hall and McPherson, 2001). However, they may be more honest accounts in some respects because the bereaved relatives do not need to either minimise their own (or the patient's) distress whilst actively caring for a patient, nor do they need to worry that criticism of healthcare services or individual professionals may, in some way, have a negative impact on the care provided, particularly when the researcher is a healthcare professional.

I felt that it was neither practical nor appropriate to validate the data by returning interview transcripts to the patients that I had interviewed for the following reasons: firstly it would not have been possible in all cases: the patients were ill and two died within a week of being interviewed; secondly, at risk of sounding patronising, reading the transcripts may have caused additional distress; thirdly, patients may have then requested that transcripts be amended, thus compromising the original data; fourthly, I would have no control over the influence of others who might read and suggest alterations to the transcripts; fifthly, I would not necessarily know if patients had died and thus could cause additional distress to grieving relatives. In the submissions to LRECs I had requested permission to re-interview some participants if I felt it necessary but this did not happen in practice as the interviews felt complete and also because there was not sufficient time. In hindsight, it may have been useful to do this as I would have not been a stranger on the second occasion and may have obtained more data regarding the more emotive issues such as 'living with dying'.

With regard to the focus groups, again I did not return transcripts to the participants for practical reasons but I have promised to send a summary of the collective findings to all participants at the conclusion of the study – this is now in preparation. (Several of these bereaved relatives have kept in contact with me by telephone or letter and I have met three who have subsequently become



involved in asbestos victims campaigning groups at conferences. Their feedback and that of professional peer groups related to my presentations<sup>19</sup> has been positive every time.)

It was difficult for me to keep notes of non-verbal communications and clues whilst conducting the interview or focus group. Additional data would have been collected by video- rather than audio-recording the interviews and focus groups, although this may have been less acceptable to participants. Although brief field notes were kept, some information was inevitably missed.

Being a researcher and also a doctor may have also influenced reflexivity or, due to the unequal power relationship, introduced bias. I attempted to reduce this effect by dressing informally, being careful with body language and speech, and stressing my role as a researcher rather than a doctor.

### 2.2.3. Practical difficulties

*Accommodation:* Facilities for the time-consuming process of data collection varied considerably, from the draughty basement store for medical records in one old hospital to generous hospitality in the 4 hospices.

*Dirty records:* The state of the notes also varied from place to place; clerical staff in one hospital were reluctant to retrieve notes because they were stored in the basement of a decaying disused hospital that was allegedly infested with fleas and rats. Some of these notes were dirty.

*Profile:* Although the intention had been to conduct the study firstly in Barrow, then in Leeds and finally in Doncaster, some of the later patients from Leeds 'overlapped' with those from Doncaster due to the unpredictability of recruitment. It became apparent that I needed to maintain a high profile for the study in Leeds and Doncaster where I was relatively unknown, otherwise recruitment seemed to decline.

*Absentees:* Two (unrelated) people who had given written consent and confirmed that they would be attending one of the focus groups did not attend on the day leaving one woman on her own (but happy to continue as a 'group of

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<sup>19</sup> A list of presentations and publications related to the study can be found in Appendix 13

one'). One of the absent women telephoned the following day to say she had a clashing engagement, nothing was heard from the other person.

*Pets and other distractions:* Practical problems due to pets occurred in two cases: in one of the early interviews a cockatiel flew around the room and screeched loudly from time to time causing deafening problems when transcribing; on another occasion, where the patient and wife were distressed by their situation (Vignette 4.2, p163), their dog, a nervous collie, sat on the microphone which was on the settee next to me and refused to move; the resulting recording was only just audible. Distractions from telephone calls from relatives or healthcare professionals occurred in three interviews and in one case a neighbour, who was in dispute with the patient being interviewed, was obviously unhappy that my car was parked (legitimately) outside her house. In another interview the patient answered the door to two Jehovah's Witnesses and then spent some time explaining that he was being interviewed.

*Colleagues:* Problems in my practice caused a major hiccup. I had discussed the 12 months funded study leave with my part-time partner and we had appointed a full-time locum as my replacement. Unfortunately when I had been away for 7 months my partner decided to leave the practice and my locum suddenly had to move away, for different and unrelated reasons. This left the practice without a doctor and so I had to return to full-time General Practice in the middle of data collection. I then needed both a half-time partner and a full-time locum in order to resume my study leave. At a difficult time for recruitment it took 8 months to find a new partner, one of my former GP trainees. As there were no locums available, my new partner was prepared to work full-time so that I could resume study leave on a half-time basis, for 10 months half-time rather than the remaining 5 months full-time. Data collection was mostly completed within this time but the disruption interfered with the momentum of the study and resulted in most of the analysis and writing up to be conducted whilst working full-time – not recommended practice.

*Other duties:* During the study, in addition to being a GP, I was employed as a hospice medical officer with responsibility for an 8-bedded unit on a 1 in 3 rota. This was arranged in 7-day blocks: in a duty week the work consisted of a daily 'ward round', admission of patients, death certification, liaison with the visiting

consultant twice a week, advice to GPs in and out-of-hours, dealing with relatives and being on call 24 hours/day for 7 days. This continued throughout the study, including when on Extended Study Leave, because there was no other medical cover available and it meant some inconvenience whilst engaged in fieldwork in Leeds and Doncaster.

*Parking:* Hospital car parks almost all charge for parking but are still frequently full. In Leeds I usually had to park at some distance from the hospital in a multi-storey car park, inconvenient for me, but worse for ill patients and their relatives.

#### 2.2.4. Rigour

Unlike quantitative research, in which tests of statistical reliability and validity are clearly established, qualitative research has been criticised for being 'unscientific', as if being scientific was the 'gold standard'. In fact even 'gold standard' quantitative studies such as randomised controlled trials have been shown to have their limitations and their results neither universally representative nor unbiased (Aoun and Kristjanson, 2005). To counter these criticisms, systems for assessing the quality of qualitative research have been proposed. The framework produced by the Government Chief Social Researcher's Office, (Spencer *et al*, 2003), with respect to research design and conduct was used to check: that I had paid attention to their guiding principles and that research should be 'contributory, defensible in design, rigorous in conduct and credible in claim'.

In considering the quality criteria suggested by Lincoln and Guba (1985) I decided key areas needed further discussion: truth value; applicability; consistency; and neutrality. Truth value was supported by the explanation of the way in which theory was grounded in the data and illustrated by multiple quotes taken from verbatim transcripts. There is bound to be some subjectivity in selecting quotes but I have tried to include contradicting quotes and explain variance when it occurs. The case study method, by examining the issues from multiple perspectives and with multiple data sources, is likely to provide a more rounded picture than a single investigation. The development of the category 'in it together' serves to illustrate the deeper exploration of the interviews (p83) and the use of triangulation of data. Applicability has been addressed by providing a clear account of the context of the study and its limitations and discussing the

findings with regard to palliative care and social medicine. Consistency has been addressed by reference to the existing literature as far as possible with discussion of findings that contrast with previous work and explanation of new findings. Neutrality could be criticised in this study given that I work in palliative medicine and had 'prior notions' of particular problems in mesothelioma as it affects patients and their families, but these issues were stated at the outset, (p 58-9), and prior knowledge is an advantage in case study work. However, I have tried to avoid imposing my notions by letting the patients and relatives speak for themselves, by using verbatim data in quotes and adding data from interviews with healthcare professionals. By setting the study in three sites I tried to ensure that my view, perhaps restricted to the situation concerning Barrow patients, was balanced by findings from other areas.

### 2.2.5. Single researcher

The mixed methods, multiple sites, case study design was an ambitious undertaking for me as an inexperienced single researcher and, although I enjoyed the field work, on many occasions I felt awash with data. When writing up the study I was frequently overwhelmed at the task of trying to reduce the thesis to a manageable size. In addition, using four methods on three sites required very careful organisation as well as the mental challenge of there being overlap of one method with another due to recruitment and other practical problems. If time had allowed it would have been easier to keep the methods separate as originally planned.

Writing an academic paper,<sup>20</sup> co-authored by my supervisors, was a valuable experience and dramatically eased the writing process, although it was still daunting. The paper was commissioned by a journal guest editor after hearing me present the findings of the interviews with patients at the 7<sup>th</sup> conference of the International Mesothelioma Interest Group in Brescia, Italy, in 2004.

Researching in palliative medicine is likely to have an emotional impact on the researcher and this was certainly true. Whilst not particularly troubled by any aspects of the fieldwork conducted in my own area, Barrow-in-Furness, I found the interviews with patients and healthcare professionals and the focus groups

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<sup>20</sup> Clayson H, Seymour J E, Noble B. Mesothelioma from the patient's perspective. (2005). *Hematol Oncol Clin Am* 19; 1175-1190.

with bereaved relatives in Leeds and Doncaster distressing. Much of this may have related to me being away from my professional and geographical 'comfort zone' and therefore added layers of anxiety were present. These included: finding the patients' homes; arranging suitable venues for the focus groups; not realising how busy the M1 motorway was at certain times; knowing that I had no medical role or influence in the localities, therefore feeling professionally vulnerable when interviewing ill people in their homes; being away from regular contact with colleagues and missing the ability to discuss some of the troubling aspects of the study; and of course, being away from home. To this day, driving up the M1 from Sheffield towards Leeds and Doncaster, retracing the route towards interviews with patients and focus groups, brings on almost overwhelming sadness. The power of this emotional reaction surprises me as I am usually regarded as more practical than emotional. However, I have chosen to work in palliative medicine.....

The privilege of being able to study exactly the subject of my choice and having the luxury of some protected time and funding from the RCGP has been much appreciated. It is sad to know that the Extended Study Leave scheme is no longer available for General Practitioners.

# Chapter 3: Medical Records Survey

## 3.1 Introduction

The intention of this survey of medical records was to obtain data on disease trajectory, burden and service usage in order to provide a broad understanding of the healthcare services provided. I surveyed the medical records of 80 deceased patients who died between 1.1.1998 and 1.1.2001 and whose certified cause of death included pleural mesothelioma: the GP, hospital and, where applicable, hospice records were examined. The sampling is described in the Methods chapter, p75-6. A proforma (Appendix 12) was used to collect the data that I then entered onto SPSS software to assist data-handling and analysis. The data are presented in the form of descriptive statistics, as they apply to each site, and collectively. Percentages, when used, are rounded up to the nearest whole number.

Details of first symptom/s, presenting and main symptoms, date of diagnosis, survival from presentation and medications for symptom control are reported in all cases regardless of survival time. Findings relating to medical interventions; attendances at outpatient clinics and GP surgeries; and hospital admissions are reported for the whole illness if patient survived less than a year, (n=50, 63%), and with respect to the last 12 months of life for those who survived more than 12 months from presentation (n=30, 37%). The phrase 'in the last year of life' is used for convenience to refer to data relating to all patients, acknowledging that most did not survive more than 12 months from presentation.

## 3.2 Epidemiology

### *Occupation and asbestos exposure*

The majority of Barrow-in-Furness patients had been skilled manual workers involved in shipbuilding and/or heavy engineering that occurred on neighbouring sites and for the same employer; both industries involved asbestos exposure. Employees often worked on short-term contracts and interchanged between shipyard and engineering depending on rates of pay and job availability. Commonly, all employment, in either the shipyard or the engineering works, was referred to by the workforce as 'working in the shipyard'.

The occupations of the Leeds patients reflect the local asbestos manufacturing industry and allied trades. The Roberts' asbestos textile factory closed in 1955 but a variety of trades using asbestos products, such as floor and ceiling tiles and insulation materials, continued for at least a further 15 – 20 years as well as major post-war reconstruction work that used asbestos cement and insulation.

The data from Doncaster reflects the influence of a large railway maintenance and construction works as a major employer as well as the power stations situated along the river Trent. Railway engine boilers were insulated by large asbestos blankets, the carriages were protected from fire risks by asbestos insulation and the brakes had asbestos linings. The power stations generated vast amounts of heat and asbestos materials were again used for insulation.

Most of the deceased patients were male, (m:f, 72:8) with a mean age of 70 years (range 45 – 94 years). As shown in Table 3.1, 65 of the 74 patients, (88%), in whom occupation was recorded, worked in industries acknowledged to expose the workforce to asbestos (HSE, 2005b). The remaining 9 patients in whom occupation was recorded included a tailoress, who may have been exposed to asbestos lagging around pipes from the steam presses; a coal miner; service man and a pile cutter who may have been exposed at work. Five of the 75, (7%), in whom occupation was recorded, could not be considered as having any likely asbestos exposure due to occupation: they were four housewives, and a secretary. Six patients, one in Leeds and five in Doncaster, had no record of asbestos exposure. It was not possible to determine the specific type of asbestos that patients were exposed to.

### *Non-occupational asbestos exposure*

Other types of asbestos exposure are also shown in Table 3.1. Family exposure usually related to contact with asbestos-contaminated working clothes, sometimes referred to as para-occupational or bystander exposure. The environmental exposures all related to living near the Leeds asbestos textile factory, presumably due to pollution of the surrounding residential area. Four patients were recorded as having more than one type of asbestos exposure: two shipyard workers also had family exposure: one had washed her husband's and son's shipyard overalls for many years; another had been exposed to his

father's shipyard overalls throughout childhood and this patient's brother had also died of asbestos-related disease; a tailoress was married to a joiner who used asbestos; and a housewife, whose parents both worked in the asbestos factory, also lived near the factory.

<b>Asbestos-related occupation</b>	<b>Barrow</b>	<b>Leeds</b>	<b>Doncaster</b>	<b>Combined</b>
Shipbuilding/engineering*	24	4		28* (35%)
Railway carriage maintenance and construction		1	16	17 (21%)
Buildings maintenance/construction	1	6	3	10 (12.5%)
Power station	1	1	3	5 (6%)
Asbestos insulation & trades**		3		3 (5%)
Stainless steel/copper industry		2		2 (3%)
Notes recording occupation	26	17	22	65 (81%)
<b>Non-occupational exposure</b>				
Family contact/bystander	2	4	0	6 (7.5%)
Environmental	0	5	0	5 (6%)
Total sample (n= 80)	26	27	27	80

**Table 3.1: Routes by which patients were exposed to asbestos**

\*One patient had been an accountant working in the shipyard

\*\* Asbestos trades included manufacture of asbestos board and an asbestos floor tile layer

### *Other asbestos-related conditions*

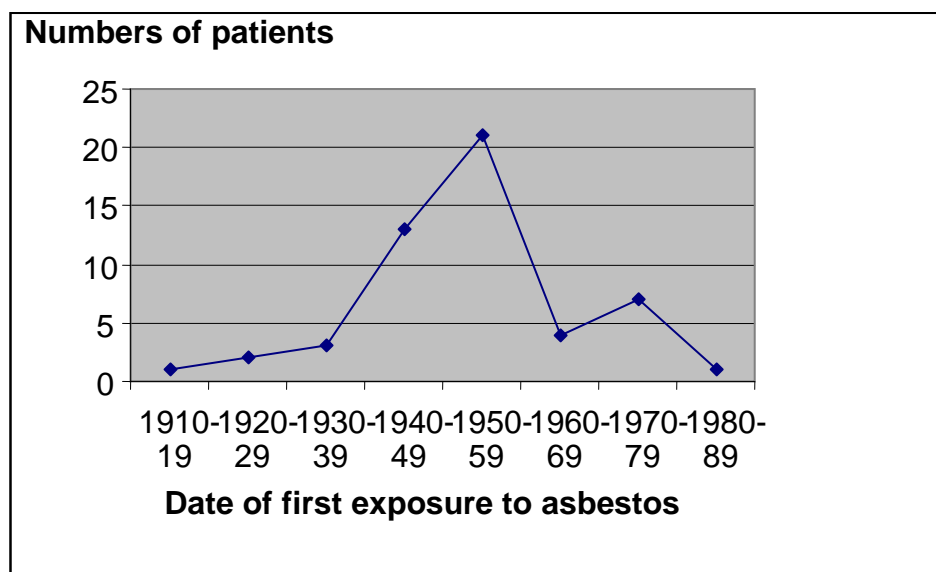
None of the 80 patients had a history of asbestosis. Twelve of the 80 patients had been known to have pleural plaques prior to the diagnosis of mesothelioma 7, (27%), in Barrow and 5, (19%), in Doncaster. Pleural plaques were not noted in any of the Leeds records<sup>21</sup>.

<sup>21</sup> This is unlikely to reflect low incidence of plaques in Leeds but is probably a recording artefact (personal communication from Dr Martin Muers, Consultant in Respiratory Medicine, Leeds, 2006)



## Latency

Latency refers to the interval between asbestos exposure and disease presentation. The date of first exposure ranged from 1919 to 1983; the majority of exposures commenced between 1940 and 1960, peaking in the 1950s.



**Figure 3.1: Date of first exposure to asbestos**

The recorded durations of exposure ranged from 1 month to 56 years and, across the three study sites, the median duration of exposure to asbestos also varied considerably, from 4 ½ years to 37 years, median 18 years. However, recording of this in medical notes also varied across the sites, Table 3.2. It was not possible to determine from the records if exposure had been continuous.

Duration of exposure to asbestos	Barrow	Leeds	Doncaster	Combined
Median duration (years)	37	4.5	18	19
Range of duration of exposure to asbestos	1-56 years	1 month - 47 years	3 - 47 years	1 month – 56 years
Numbers of notes with duration recorded	19	10	19	50
Missing data	7	17	6	30
Total in the study (n=)	26	27	27	80

**Table 3.2: Duration of exposure to asbestos**

Latency also varied across the three sites, between 28 and 47 years, as illustrated below, Table 3.3.

Exposure to disease presentation interval	Barrow	Leeds	Doncaster	Combined
Median interval (years)	47	28	47	45.5
Range (years)	29 - 79	20 - 49	15 - 62	15 - 79

**Table 3.3: Latency: Interval in years between first asbestos exposure and disease presentation**

### 3.3 Clinico-pathological features

#### *Presentation*

Breathlessness, chest pain and cough, singly or in combination, accounted for the majority, (88%), of symptoms at presentation to medical services; in eight patients, (10%), including two who had chest infections, mesothelioma was an incidental finding, Table 3.4:

Presenting symptom	Barrow	Leeds	Doncaster	Combined
Breathlessness	11	10	11	32 (40%)
Chest pain	4	7	8	19 (24%)
Cough	5	4	3	12 (15%)
Breathlessness and chest pain	2	2	3	7 (9%)
Chest infection	2			2 (3%)
Incidental on CXR	2	2	2	6 (8%)
Sample in study (n=80 )	26	27	27	80

**Table 3.4: Main presenting symptoms**

Most patients presented initially to their GP. In 35 of the 80 cases, (44%), the interval between symptom onset and attending the GP was recorded or could be calculated and ranged from the same day to 212 days, mean 43 days, median 17 days. Acute presentations were common: almost half the patients (34/72, 47%) in whom the details could be ascertained, were admitted to hospital on the day that they presented to their GP or to hospital. It was impossible to determine from the records the route by which most of these

emergency patients became admitted, although at least 5 of the 34 patients presented directly to an Accident and Emergency department, Table 3.5:

<b>Symptom onset to presentation to hospital (days)</b>	<b>Barrow</b>	<b>Leeds</b>	<b>Doncaster</b>	<b>Combined</b>
Within 7 days	7	4	0	11
Within 14 days	2	4	1	7
Within 21 days	2	3	3	8
Within 28 days	1	2	1	4
Cumulative at 28 days	12	13	5	30 (37.5%)
Within 84 days	8	7	8	23
Cumulative at 84 days	20	20	13	53 (66%)
More than 6 months	2	1	2	5
Missing data	4	6	12	22
Median interval between symptom onset and presentation to hospital (days)	30	30	80	36
Range of intervals in days	0-260	2-221	11-242	0-260
Number in sample (n= )	26	27	27	80

**Table 3.5: Interval between onset of symptoms and presentation to hospital (includes all routes of access to hospital)**

In 16 cases, (20%), the GP had referred the patient for a chest x-ray within a week of first surgery presentation, and 29 (36%) patients attended hospital within 3 weeks of first attending their GP. The median interval between onset of symptoms and first attendance at hospital was 36 days, Table 3.5. The variation in median interval between symptom onset and presentation to hospital from 30 days in Barrow and Leeds to 80 days in Doncaster is striking, as is the range across the sites from same day to 260 days, although data were missing for almost half the Doncaster patients. Examination of the records of patients who took longer than 6 months to be seen in hospital revealed that in most cases they had complicated medical histories and concurrent chronic conditions that may have obscured the development of a new illness. Four patients had no recorded contact with their GP related to mesothelioma symptoms prior to admission. Seven patients were already attending respiratory medicine

outpatient clinics at the time of presentation of mesothelioma symptoms, 3 of these with pleural plaques.

### *Investigations in the last 12 months of life*

Multiple investigations were recorded but it was not always possible to ascertain the purpose of interventions from the records. In some cases it was obvious, for example, open pleural biopsy was invariably a diagnostic procedure, but a VATS<sup>22</sup> procedure could be performed to drain an effusion, take a biopsy and/or perform pleurodesis. Most procedures were performed up to three times per patient but chest x-rays were performed more frequently, Table 3.6:

Investigation performed	Number of investigations /number of patients who had those investigations			
	Barrow N=26	Leeds N=27	Doncaster N=27	Combined N=80
CXR	114/26	82/25	116/25	312/78
CT scan	25/21	33/24	9/9	67/54
Needle biopsy (pleura)	16/14	30/24	20/18	66/56
VATS biopsy "	1/1	13/12	11/10	25/23
USS abdomen	6/5	7/7	7/7	20/19
Bronchoscopy	5/5	6/6	7/7	19/19
USS thorax	1	6/4	6/5	13/10
Open biopsy "	4/4	4/3	5/5	13/12
Other biopsy	0	4/4	6/6	10/10
Upper GI endoscopy	2/2	3/3	3/3	8/8
MRI scan	6/6	0	0	6/6
Isotope bone scan	1	2/2	3/3	6/6
Lower GI endoscopy	1	2/2	0	3/2
Laparotomy	1	2/2	0	3/3
Barium swallow	1	0	1	2/2
Ventilation/perfusion scan	1	0	1	2/2
Laryngoscopy	1	0	0	1/1

**Table 3.6: Investigations performed in the last 12 months of life** (in order of frequency across the 3 sites combined)

<sup>22</sup> VATS = Video-assisted thoracoscopy

### *Confirmation of mesothelioma*

The median interval between presentation to hospital and confirmation of diagnosis in those diagnosed during life was 79 days (111 days, mean). Histological diagnosis of mesothelioma or suspected mesothelioma was obtained before death in 62 of the 80 cases, (78%), Table 3.7; in many cases this required several investigations. The specific histological type was confirmed in around half of these diagnoses (30/62), in 13 cases there was no histological diagnosis. The five incorrect diagnoses were as follows: anaplastic large cell carcinoma lung arising from the pleura with lung metastases; reactive mesothelial cells; carcinoma oesophagus, poorly differentiated lung cancer; infection and pleural plaque. In all cases mesothelioma was confirmed at post mortem examination.

<b>Histology (ante mortem)</b>	<b>Barrow</b>	<b>Leeds</b>	<b>Doncaster</b>	<b>Combined</b>
Mesothelioma, unspecified	6	11	3	20
Epithelioid	2	9	7	18
'Probable' mesothelioma	7	2	3	12
Sarcomatous/desmoplastic	2	2	3	7
Mixed	0	2	3	5
Other malignancy	1	0	2	3
Other diagnosis	1	0	1	2
Missing data	7	1	5	13
Totals	26	27	27	80

**Table 3.7: Histology results during the patients' illness**

Ante mortem histology was obtained from either pleural biopsy or pleural fluid in 57 of the 63 cases, (90%), Table 3.7. VATS procedures were performed on 23 patients, twice in two cases, and most of these procedures were performed on patients from Leeds in the local thoracic surgery unit. Table 3.8 demonstrates no incorrect diagnoses in the Leeds patients.

Histology site	Barrow	Leeds	Doncaster	Combined
Pleura	9	18	18	45
Pleural fluid	9	1	1	11
Lung	0	1	1	2
Metastasis	0	1	2	3
Other	1	0	1	2

**Table 3.8: Site from which ante mortem histology for mesothelioma was obtained**

### *Symptom burden*

Physical symptoms recorded during the patients' illness demonstrate the preponderance of shortness of breath and pain, and also that cough and weight loss affected nearly half the patients, Table 3.9:

Symptom	Barrow	Leeds	Doncaster	Combined
Short of breath	26	25	26	77 (96%)
Pain	24	25	24	73 (91%)
Cough	12	9	12	33 (41%)
Weight loss	14	8	11	33 (41%)
Anorexia	6	8	6	20 (25%)
Sweating	8	4	2	14 (18%)
Nausea	5	5	1	11 (14%)
Fatigue	3	5	2	10 (13%)
Dysphagia	3	2	4	9 (11%)
Constipation	0	3	3	6 (8%)
Ascites	3	2	1	6 (8%)
Vomiting	1	3	1	4 (5%)
Painful metastasis	3	0	1	4 (5%)
Totals	26	27	27	80

**Table 3.9: Physical symptoms in mesothelioma**

When psychological symptoms were aggregated, (anxiety, depression, emotional distress and psychiatric disorder), the recorded symptoms varied across the 3 sites. However, the data reveal that almost half of the patients were recorded as having some form of psycho-emotional distress, Table 3.10. In addition, social problems were recorded in 13 patients (16%).

	<b>Barrow</b>	<b>Leeds</b>	<b>Doncaster</b>	<b>Combined</b>
Number of patients with recorded psycho-emotional symptoms	14	17	6	37 (46%)
Totals	26	27	27	80

**Table 3.10: Recorded psychological symptoms**

### *Pleural effusions*

Pleural effusions occurred at some stage during the illness in 62 of 80 (78%) patients. In 15 patients, the effusions had resolved prior to the last year of life, in 10 cases this appeared to follow successful pleurodesis, Table 3.11. (see below, section 3.4, and Box 1.2)

	<b>Barrow</b>	<b>Leeds</b>	<b>Doncaster</b>	<b>Combined</b>
Number of patients with effusions	18	23	21	62 (78%)
Number whose effusions resolved prior to last 12/12 of life	3	9	3	15 (19%)
Totals in study	26	27	27	80

**Table 3.11: Number of patients who had pleural effusions**

## **3.4 Clinical management**

### *Pleural aspiration (thoracentesis)*

All patients who had pleural effusions were treated with pleural aspiration. Occasionally chest drains were left in situ for some days but duration and volumes of fluid drained were often unclear in the notes. Forty seven patients who required pleural aspiration in the final year of life had 170 procedures.

Number of pleural aspirations per patient with effusion in last year of life	Barrow	Leeds	Doncaster	Combined
0	11	12	9	32
1	1	3	9	13
2	1	8	4	12
3	3	2	2	7
4	0	2	1	3
5	2	0	2	4
6	2	0	0	2
7	3	0	0	3
11	1	0	0	1
14	1	0	0	1
22	1	0	0	1
Total number of pleural taps	102	33	37	170
Total patients with effusions in last yr of life	15	14	18	47
Number of patients in study	26	27	27	80

**Table 3.12: Pleural aspirations per patient in the last year of life**

As shown in Table 3.12, pleural aspiration was conducted more often in Barrow than in Leeds and Doncaster: three Barrow patients (B7, B27, B24), accounted for most of this variation. They required pleural aspirations 11, 14 and, exceptionally, 22 times respectively during their last 12 months of life, Table 3.13. The last patient, (B24), survived 29 months from presentation and had 32 pleural aspirations in that time.

### *Pleurodesis*

Pleurodesis was attempted in 35 (56%) of the 62 patients who had effusions and achieved an overall success rate of 63% in that no further effusions were recorded. However, there were differences in the success rates across the 3 sites as shown in Table 3.13. Three patients had pleurodesis twice and one patient three times but it was only finally successful in one of these patients.



Details of pleurodesis	Barrow	Leeds	Doncaster	Combined
Number receiving pleurodesis	8	16	11	35
Number of procedures	10	18	13	41
Talc pleurodesis	3	12	7	22
Tetracycline pleurodesis	4	2	2	8
Unspecified pleurodesis	3	4	4	11
Mean number of pleural aspirations prior to pleurodesis	6*	3	2	
Number (%) successful	3 (30%)	15 (83%)	8 (62%)	26 (63%)
Referred to thoracic surgery	4	12	9	25
Data missing, no of cases	6	6	4	9

**Table 3.13: Details of pleurodesis**

In many cases it could not be ascertained where the procedure had been performed, that is, whether it had been in theatre as an operative procedure conducted by a thoracic surgeon or as a ward procedure possibly performed by a physician: data were missing in almost a third of cases. Similarly, data were missing in almost a quarter of cases regarding the material used for the procedure (sterile iodised talc or tetracycline). The three Barrow patients who required the most aspirations described in the previous section had all undergone pleurodesis without success. Medical pleurodesis with tetracycline and two attempts at VATS talc pleurodesis had failed in one patient (B24), single procedures had been conducted for the other two patients; in each case pleurodesis was attempted after 4 or 5 pleural aspirations. Ten of 15 cases in which pleural effusions had resolved prior to the last 12 months of life had previously received successful pleurodesis, in one case this was performed twice; 8 of these 10 successful cases were in Leeds.

There was little in the notes to suggest a standard approach to breathlessness although many patients were prescribed bronchodilators and oxygen as well as benzodiazepines, but it was not possible in most cases to determine whether the latter were prescribed for breathlessness or anxiety. There was no mention in the notes of breathless management techniques or programmes.

## *Oncological treatments: chemotherapy and radiotherapy*

Two patients from Barrow and four patients from Leeds received palliative chemotherapy, 7.5% of the total: one patient was recorded as participating in a clinical trial; the other four records were unclear. No patients from Doncaster were recorded as having had chemotherapy. Less than half the patients had radiotherapy and the referral rate varied across the three sites, Table 3.14:

<b>Radiotherapy</b>	<b>Barrow</b>	<b>Leeds</b>	<b>Doncaster</b>	<b>Combined</b>
Numbers of patients referred for radiotherapy	4 (15%)	19 (70%)	9 (33%)	32 (40%)
Prophylaxis to port sites	2	10	5	17
Skin metastasis	1		2	3
Bone metastasis		2		2
Chest pain	1			1
Missing data	0	7	2	9
Total number of patients	26	27	27	80

**Table 3.14: Numbers of patients referred and the reasons for radiotherapy.**

### *Surgery*

Only two of the 80 patients, both from Leeds, had palliative cyto-reductive (debulking) surgery, they both survived less than a year from presentation. One had decortication three months after presentation and survived a further 7 months; histology subtype was not recorded. The other man had extension of the tumour through the chest wall and this was resected, at the same time as decortication and insertion of a Gortex™ patch, 6 months after presentation. In this case several diagnoses had been considered, and even with the benefit of an extensive surgical tissue sample, it was not confirmed as sarcomatoid mesothelioma until a month before he died, 5 months following surgery.

### *Management of pain*

Strong opiates had been prescribed for 68 (85%) of the 80 patients across all settings, most commonly oral morphine. Daily maximum doses of morphine and morphine-related analgesics are shown in Table 3.15 below; hydromorphone

and diamorphine doses have been calculated as 24-hour oral morphine equivalents.

<b>Maximum daily opioid doses (oral morphine equivalents mg/24 hrs)</b>	<b>Barrow</b>	<b>Leeds</b>	<b>Doncaster</b>	<b>Combined</b>
Oral morphine (mg/24 hours) mean	131	108	165	135
Oral morphine median daily dose, in mg				100
Range of doses	15-520	15-300	20-640	15-640
Patients taking oral morphine	18	18	18	54 (68% of patients)
Subcutaneous (sc) infusion of diamorphine as mean dose oral morphine mg/24 hours	177	189	246	204
Range of doses	30-390	30-900	15-1200	15-1200
Patients receiving sc infusion of diamorphine	11	6	12	29 (36% of patients)
Median dose of sc diamorphine as oral morphine equivalent, mg/24 hours				90
Hydromorphone	255	0	0	255
Totals (no of patients)	26	27	27	80

**Table 3.15: Maximum morphine opiate doses as 24-hour equivalents to oral morphine<sup>23</sup>**

Two patients appeared to have had difficult pain management problems: one patient (B15) received epidural diamorphine, 90mg/24 hours equivalent to ~1350<sup>24</sup> mg oral morphine/24 hours (see Vignette 3.1, p115). In this case, the 24-hour oral morphine equivalent doses of *other* opiates (see Table 3.16) were also the highest recorded in the study. From his hospice notes, this patient had been prescribed multiple analgesic agents, see Table 3.18. The other patient had received intrathecal morphine but the dose was not found in the notes.

<sup>23</sup> Conversion factors used in the calculations from Twycross (1997:67)

<sup>24</sup> Conversion factor for epidural to oral is not exact, approximate figure based on Mercadante (1999).

Mean doses of other opiates	Barrow	Leeds	Doncaster	Daily oral morphine equivalents,mg/24hrs
Transdermal fentanyl mcg/hour (range)	50 (120-240)	37.5 (25-50)	0	~150-210
Number of patients prescribed fentanyl	6	6	0	
Oral methadone mgs/24 hours *	110	0	0	? up to 1100 <sup>25</sup>
Number of patients prescribed methadone	1	0	0	

**Table 3.16: Doses of other opiates**

\*Prescribed for patient B15 before epidural diamorphine.

The vignette below, describes multiple approaches to the management of particularly severe pain affecting one patient:

Patient B15 was a retired shipyard engineer in his 70s. He had been exposed to asbestos for 45 years from his time as an apprentice fitter and turner to later working in ships' boiler rooms. He presented with chest and back pain, mesothelioma was diagnosed on clinical grounds (biopsy inconclusive), and a CT scan showed tumour infiltration of thoracic vertebrae. Interventions to control his severe pain included right-sided thoracic sympathectomy and paravertebral block and he was prescribed the whole range of medications used for complex pain at that time: morphine, methadone, fentanyl, NSAID, carbamazepine, amitriptyline, and ketamine. He was too unwell to travel 70 miles for palliative radiotherapy. Pain was eventually controlled in the hospice with an epidural infusion of diamorphine and an intravenous infusion of midazolam. He survived 12 months from presentation and in that time saw his GP 8 times, attended 10 outpatient appointments, had 3 hospital admissions, and finally was admitted to a hospice where he died 7 weeks later.

### **Vignette 3.1: A patient with severe pain (patient B15)**

#### *Other analgesics*

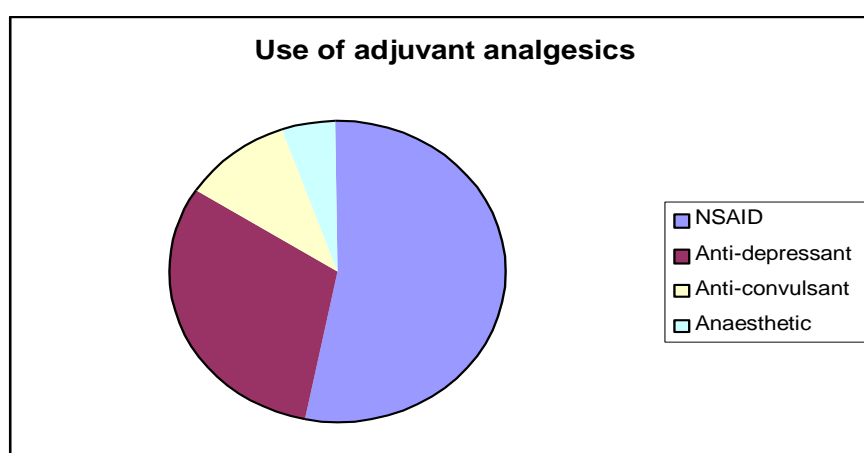
Across the three sites, the prescribed adjuvant analgesics were mainly non-steroidal anti-inflammatory drugs and, to a lesser extent, anti-depressants. However, it was not possible to establish from the notes whether the antidepressants were prescribed for neuropathic pain or for depression.

<sup>25</sup> The calculation of the equivalent dose of oral morphine is not straightforward due to the long half-life of methadone and its effect on multiple receptors, hence this is an estimation (Twycross 1997:35).

Adjuvant analgesic	Barrow	Leeds	Doncaster
Non-steroidal anti-inflammatory drug	15	14	10
Antidepressant	11	9	3
Anticonvulsant drug	4	3	1
Anaesthetic (ketamine)	1	2	1

**Table 3.17: Numbers of patients receiving adjuvant analgesic medications**

The overall prescribing of these medications is shown in Figure 3.2, but in many cases they were used in combination (Table 3.18)



**Figure 3.2: Prescribed adjuvant analgesics**

Twelve of the 80 patients, (15%), were prescribed two or more opiates<sup>26</sup> plus a variety of other analgesics including adjuncts usually used for inflammation or neuropathic pain, Table 3.18:

<sup>26</sup> Morphine and diamorphine were counted as one opiate due to the common practice of converting oral morphine to subcutaneous diamorphine.

Medication	Patient's ID											
	B1	B15 <sup>27</sup>	B18	L1	L8	L17	L21	L24	L26	L27	D6	D13
Number of opiates	3	3	2	3	2	4	2	3	2	3	2	2
NSAID	y	y	y	y		y	y	y	y	y	y	y
Anticonvulsant		y		y					y			
Antidepressant	y	y	y		y		y	y				y
Anaesthetic		y								y		y
Sedative	y	y	y		y			y	y	y	y	

**Table 3.18: Patients prescribed two or more opiates and adjuvant analgesics**

*Informing the patient of the diagnosis*

A consultant disclosed the diagnosis in most cases, Table 3.19. In two of these cases, it appeared that the patients were told that they probably had mesothelioma in spite of histology reports indicating other conditions. Patients with shorter survival times were more likely to have no record of being informed of the diagnosis compared with those living more than 12 months, (43% compared with 13% of patients).

Who informed the patient of the diagnosis?	Barrow	Leeds	Doncaster	Combined
Consultant	11	14	13	38
Registrar <sup>28</sup>	5	8	5	18
GP		1		1
Missing data	10	4	9	23
Totals	26	27	27	80

**Table 3.19: Who informed the patient of the diagnosis?**

<sup>27</sup> See Vignette 3.1, page 115, for an account of the management of this patient's pain

<sup>28</sup> In one case a surgical registrar informed the patient by letter that the suspected diagnosis of mesothelioma had been confirmed by a repeat biopsy.

### 3.5 Service usage

#### *Referral to specialists*

In the last twelve months of life, patients with mesothelioma attended outpatient appointments five times on average, range 0 to 13 times: 80 patients attended 411 appointments of which only 8% were for palliative medicine. Table 3.20 illustrates the most frequently attended clinics and demonstrates co-morbidities, in that 14% of patients were also being treated for a variety of conditions unrelated to mesothelioma (and see Table 3.26).

<b>Outpatient department</b>	<b>Respiratory medicine</b>	<b>Oncology/ radiotherapy</b>	<b>Palliative medicine</b>	<b>Thoracic surgery</b>	<b>Pain clinic</b>	<b>Other clinics</b>
Numbers of appointments	194	96	33	31	1	56
% of total appointments	48%	23%	8%	8%		14%

**Table 3.20: Details of outpatient appointments attended in last year of life**

Just under half of the 80 patients (39, 49%), were referred to palliative medicine but in 2/3 this referral was made within two months of death and in four cases, within a week of death, Table 3.21. However it was not always clear if patients had accessed palliative medicine advice via Macmillan nurses, either hospital or community-based, or by direct referral, and it may be that referral pathways differed across the three sites – this was not clarified. Only one of the 80 patients was recorded as having been referred to a specialist pain service, but this may reflect missing data as two patients received interventions usually performed by pain specialists: intrathecal and epidural catheters for analgesia.

<b>Time of referral to palliative medicine</b>	<b>Numbers of patients N=39</b>
Within a week of death	4
Between 1 and 4 weeks before death	11
Between 1 and 2 months before death	11
2 to 14 months before death	13

**Table 3.21: Timing of referral to palliative care**

### *GP involvement*

In the year before death, most patients consulted their GP frequently: mean 11, median 10, range 0-41, consultations per patient. Almost half of these consultations were home visits: mean 4, median 6, range 0 - 40 visits per patient. Data recording varied: one GP exceptionally recorded 40 visits to one patient and so the data must be regarded with some caution. Thus, 80 patients with mesothelioma accounted for almost 900 consultations with their GPs, Table 3.22. GP notes recorded consultations in 13 cases with relatives.

	<b>Barrow</b>	<b>Leeds</b>	<b>Doncaster</b>	<b>Combined</b>
Total number of GP consultations	289	350	254	893
Number of consultations recorded as home visits	104 (36%)	194 (55%)	116 (46%)	414 (46%)

**Table 3.22: GP consultations in last year of life**

### *Hospital admissions*

Most patients were admitted at least two or three times during their last year of life: 72 patients, (90%), had a total of 196 admissions to hospital in their last year of life, the majority of these were due to pleural effusions, Table 3.23.



	Barrow	Leeds	Doncaster	Combined
Patients requiring 1 hospital admission	5	7	2	14 (18%)
“ 2 hospital admissions	5	9	7	21 (26%)
“ 3 “	5	3	9	17 (21%)
“ 4 “	6	4	4	14 (18%)
“ 5 “	2	2	1	5
“ 8 “	0	0	1	1
Total number of admissions	64	60	72	196
Number of hospitals to which patients were admitted	2	2	3	7
Number of patients not admitted	3	2	3	8
Totals	26	27	27	80

**Table 3.23: Hospital admissions in last year of life**

The reasons for 178 mesothelioma-related admissions are shown in Table 3.24. In addition, there were five admissions for unrelated medical problems and 13 admissions for unrelated surgical, mainly urological, problems. Eight patients, (10%), were not admitted to hospital during their last year of life. All 8 patients survived at least two years from presentation and, although they all had effusions early in their illness, pleurodesis had been successful in 7 cases.

	Barrow	Leeds	Doncaster	Combined
Pleural effusion	34	18	23	75
Dyspnoea	6	3	3	12
Chest pain/pain control	6	7	6	19
Chest infection	2	5	0	7
Pneumothorax	5	1	0	6
Deterioration/terminal care	4	7	3	14
Biopsy	0	5	11	16
Pleurodesis	1	0	3	4
Pleurectomy/debulking	0	1	1	2
Mesothelioma complications*	0	6	8	14
Radiotherapy	1	1	2	4
Chemotherapy	0	5**	0	5
Endoscopy	0	1	0	1

**Table 3.24: Reason for hospital admission**

\*Mesothelioma complications included anaemia requiring transfusion (n=4), ascites (due to extension through the diaphragm) requiring paracentesis (n=6); deep vein thrombosis; superior vena cava obstruction; chemotherapy side effects; and chest wall mass (all n=1)

\* \*Only four of the five received chemotherapy, the fifth patient was too ill.

### *Day Unit admissions*

Pleural aspirations accounted for most admissions to Day Units: exceptionally, one Barrow patient (B24), attended 22 times for pleural aspiration in his last 12 months of life, Table 3.25. Seven admissions were for surgical procedures or investigations unrelated to mesothelioma, including cataract extraction; excision of lipoma; catheter change; and femoral arteriogram.

	<b>Barrow</b>	<b>Leeds</b>	<b>Doncaster</b>	<b>Combined</b>
Pleural aspiration	40	2	5	47
Chemotherapy	3	7	0	10
Surgical procedure	2	1	4	7
Pleural biopsy	4	0	1	5
Bronchoscopy	3	0	0	3
Upper GI endoscopy	2	0	0	2
Radiotherapy	2	0	0	2
Pleurodesis	1	0	0	1
Other investigation	1	0	0	1

**Table 3.25: Reasons for attendance at Day Unit**

### *Hospice admissions*

Barrow patients accessed a hospice 9 miles away, Leeds patients could be referred to 2 hospices at opposite sides of the city, Doncaster patients had access to one hospice on the outskirts of the city. A third of the patients accessed hospice inpatient care and 30% died in a hospice: Table 3.26:

	<b>Barrow</b>	<b>Leeds</b>	<b>Doncaster</b>	<b>Combined</b>
Number of patients admitted to hospice	5	13	9	27 (34%)
Total number of admissions to hospice	8	17	13	38
Average length of stay in days	18	12	9	16
Range of length of stay in days	9-44	2-33	2-17	2-44
Number who died in the hospice	5	12	7	24
Number of hospices	1	2	1	4

**Table 3.26: Hospice admissions and deaths**

### *Co-morbidity*

Although 25% of patients had no recorded concurrent medical problems, the majority had one or more problems as shown in Table 3.27. Fifty five patients (69%) were recorded as having smoked, although only 7 (9%) were smokers at the time of presentation.

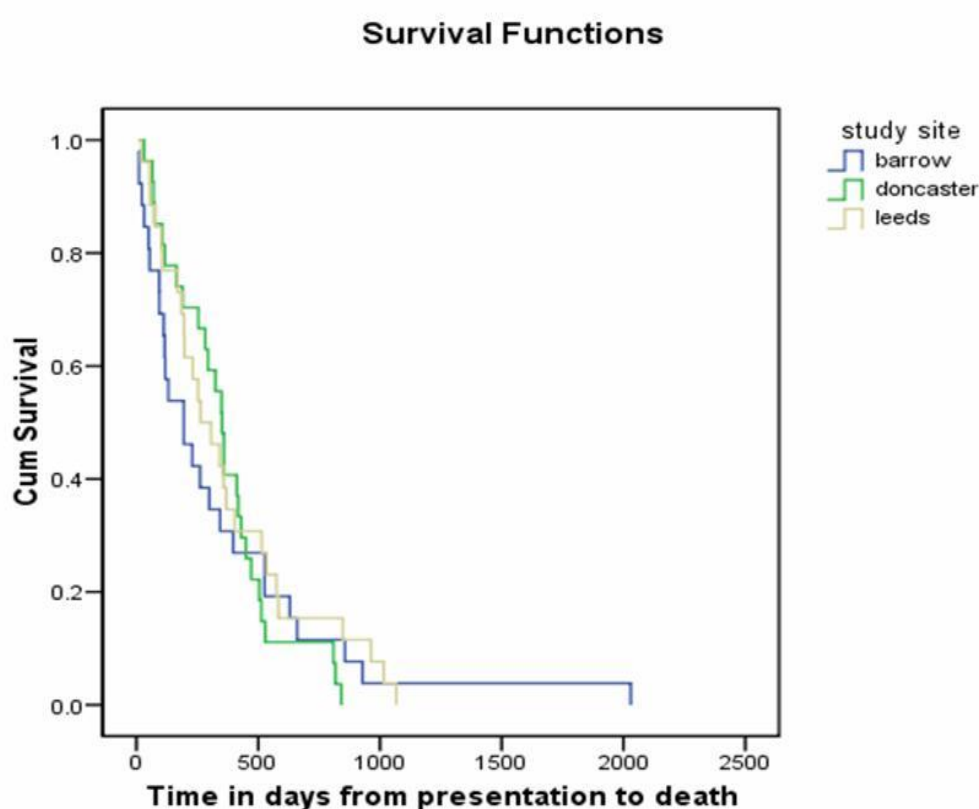
	<b>Barrow</b>	<b>Leeds</b>	<b>Doncaster</b>	<b>Combined</b>
No concurrent conditions	6	7	7	20 (25%)
Medical problem	20	19	20	59 (74%)
Surgical problem	4	5	5	14
Urological problem	7	2	3	12
Orthopaedic problem	2	3	1	6
ENT problem	1	0	0	1
Ophthalmological problem	1	1	1	3
Psychiatric problem	1	3	0	4 (5%)
Recurrent pneumothorax	2	2	0	4

**Table 3.27: Concurrent medical problems**

## 3.6 Dying and death

### *Survival*

Over half the patients died within 12 months from presentation: 50/80 (63%). Overall median survival from the date of presentation to secondary care for all patients was 294 days; the median survival in all three sites was less than twelve months as demonstrated in Figure 3.3:



**Figure 3.3: Kaplan-Meier survival curves by location**

### *Place and mode of death*

Barrow and Doncaster data showed similar distributions of place of death but Leeds patients with mesothelioma were twice as likely to die in a hospice, Table 3.28. Patients with apparently severe pain were also more likely to die in a hospice: of the 12 patients who were prescribed more than one opiate plus

other medications for pain (Table 3.18, page 117), 8 died in a hospice and three in hospital; place of death was not recorded in the remaining case.

	<b>Barrow</b>	<b>Leeds</b>	<b>Doncaster</b>	<b>Combined</b>
Hospital	15	10	11	36 (45%)
Home	6	1	4	11 (14%)
Hospice	5	12	7	24 (30%)
Nursing home		1	1	2 (2.5%)
Ambulance			1	1 (1%)
Missing data	0	3	3	6 (7.5%)
Total	26	27	27	80 (100%)

**Table 3.28: Place of death**

Mode of death data was retrieved from nursing as well as medical records (medical records frequently failed to record this information). Arbitrarily, distress unrelieved for at least one hour prior to death was the criterion for major distress, distress for less than an hour as minor distress. Data available for 47 patients revealed that 10 patients (21%) had died with unrelieved distress lasting for over an hour (Table 3.29):

	<b>Barrow</b>	<b>Leeds</b>	<b>Doncaster</b>	<b>Combined</b>
Coma or peaceful	12	7	12	31 (66%)
Minor distress	1	1	0	2 (4%)
Major distress	5	2	3	10 (21%)
Sudden	0	1	3	4 (9%)
N=	18	11	18	47
Missing data	8	16	9	33
Total	26	27	27	80

**Table 3.29: Mode of death**

Resuscitation was attempted in four patients, three in Barrow and one in Doncaster: in hospital in two cases, once at home, and once in an ambulance, Box 3.2. Mesothelioma had been the confirmed or presumed diagnosis in each of these four cases.

*A 94 year-old former shipwright with recurrent pleural effusions was admitted for pleurodesis but was too ill. Two days after admission he collapsed; resuscitation was attempted but failed. Mesothelioma had been the 'working diagnosis' for 6 months.*

*An 82 year old retired shipyard worker, suffering from dementia and 'presumed' mesothelioma, collapsed at home just before a GP visited him. The GP attempted resuscitation 'briefly' before confirming that the patient was dead. It was not clear from the notes if this was the patient's own GP.*

*A 67 year old retired shipyard painter with suspected mesothelioma was readmitted to hospital just a day after discharge following pleural aspiration. He was suffering from severe shortness of breath then collapsed. Resuscitation was attempted on the High Dependency Unit, unsuccessfully.*

*A 55 year old pipe lagger with mesothelioma became acutely short of breath at home and collapsed. His daughter dialed 999 for an ambulance and the crew attempted to resuscitate the man in the ambulance, unsuccessfully*

### **Box 3.2: Details of resuscitation procedures.**

## **3.7 Summary**

The proportion of cases with a history of occupational asbestos exposure, 88% of those in whom occupation was recorded, agrees with other UK studies and also relates to purposive sampling in specific industrial locations (Yates *et al*, 1997; Chapman *et al*, 2006). Some patients had a history of multiple exposures to asbestos, recorded as occurring in 5% of the records survey sample, although in 40% of the patients interviewed. This was often related to several generations of one family living close to, and working in, the same asbestos-related industry or, alternatively, to experiencing frequent job changes in times of economic hardship.

The shorter median duration of exposure to asbestos for the sample from Leeds reflects the different employment situation compared with the other sites: Barrow and Doncaster both had a continuing single major employer, shipyard/engineering and railway plant works respectively, but the asbestos factory in Leeds closed in 1955. Latency between exposure and disease presentation of 47 years in the Barrow and Doncaster samples, and the shortest latency of 15 years, agrees with previous UK studies that state 15 – 50 years, and a mean latency of 41 years (Yates *et al*, 1997; Doll, 1985). The shorter latency of 28 years in Leeds must be viewed with caution: exposure data was

recorded in only 10 of 27 notes in the Leeds sample as opposed to Barrow and Doncaster in which data was recorded in 19 of 26 and 19 of 27 cases respectively.

In common with other published studies, breathlessness, chest pain and cough accounted for the majority of presenting symptoms (BTS, 2001; Edwards *et al*, 2000). Symptoms preceding the presentation to GP or hospital were difficult to determine from the records and may reflect the often insidious development of mesothelioma.

The interval between symptom onset and presentation to a GP, was short (mean 43 days, median, 17 days), and 66% had presented to hospital by 84 days. In contrast, seven of 8 patients with mesothelioma included in a questionnaire survey of lung cancer patients reported feeling unwell for between 6 and 12 months before attending their GP, although this was a considerably shorter time than the 2 to 4 years reported by 31% of patients with lung cancer (Krishnasamy and Wilkie, 1999:50).

The median interval between symptom onset and presentation to hospital of 36 days relating to the mesothelioma patients in the current study is considerably shorter than the delay in presentation of lung cancer, mean 138 days (Thompson and Hetzel, 1997). This may well reflect the more dramatic presentation of mesothelioma compared with lung cancer due to the higher incidence of pleural effusion (requiring hospital treatment) and/or pain (Cooley, 2000; Hawley *et al*, 2004). The figures for the intervals between symptom onset to GP and symptom onset to hospital appear contradictory but they relate to different samples: not all patients presented to their GP, some attended hospital directly. The median time from presentation at hospital to diagnosis of 79 days is considerably longer than the 21 days in lung cancer (Krishnasamy and Wilkie, 1999: 55)

The presenting symptoms agree with other studies with most patients presenting with shortness of breath and or pain (Robinson, 2005; Hillerdahl, 1983; Yates *et al*, 1997; Lee, 2000). The incidence of pleural effusions, 78%, is similar to that found in previous studies, (Robinson *et al*, 2005; Hillerdal, 1983), and accounts for the acute presentations and multiple interventions. The lack of

any recording of pleural plaques in Leeds patients could be due to record-keeping practice: usually around 20% of patients with mesothelioma have pleural plaques, (Robinson *et al*, 2005), as in the Barrow and Doncaster data.

The recorded clinical procedures demonstrate the complexity and burden of procedures borne by patients in their last year of life in order to establish the diagnosis or monitor the condition and to manage complications such as recurrent pleural effusions. The majority of needle biopsies were not CT-guided in this study and yet 'blind' needle biopsies are reported to yield at most 50% positive histology (Munavvar, 2006). The easier access to thoracoscopy in Leeds probably explains the apparent greater diagnostic accuracy in the Leeds patients (Table 3.7, p108), although the higher prevalence of mesothelioma in Leeds would also result in greater experience in the examination of histological specimens. Barrow patients were at a disadvantage due to the distance from the nearest thoracic surgery unit, 80 miles away, (for both inpatient and outpatient services), and this is the most likely explanation for the low rate of VATS procedures compared with the other two sites that had easier access.

On average each patients had 7 investigative procedures plus four pleural aspirations. The number of pleural aspirations was much higher in Barrow than in the other two sites. Only one of the patients in the study had undergone pleurectomy and he was initially thought to have *benign* recurrent effusions; ironically, his pleurectomy specimen provided the diagnosis of mesothelioma. Data regarding pleurodesis were often incomplete but it is interesting to note that tetracycline had been used in 22 patients despite evidence that talc is superior (Martin-Ucar and Waller, 2006:256).

Prophylactic radiotherapy prevents tracking of the disease through port sites (and also has been shown to reduce chest pain in up to 50% of cases, although it is not recommended for chest pain) (Boutin *et al*, 1995). The data again illustrate the relatively low rate of referral for Barrow patients, but the nearest radiotherapy unit is 70 miles away. It is interesting that only half of the patients who had pleurodesis were recorded as having received radiotherapy to port sites, although this is recommended practice in order to prevent tumour tracking; however, missing data make interpretation difficult (BTS, 2001). However, a recent study suggests that prophylactic radiotherapy may not be as



effective as thought previously and should perhaps be reserved for 'high risk' cases (Chapman *et al*, 2006). The proportion receiving chemotherapy (7.5%) reflects the disappointing results of clinical trials at the time of the study. In a recent audit of patients with mesothelioma, 17% received chemotherapy: this was around half of those who were assessed as suitable for the treatment (Chapman *et al*, 2006). Patients from Leeds, a regional cancer centre, were most likely to be referred for chemotherapy, radiotherapy and surgery, although the latter numbers were small. Barrow patients, at considerable distances from tertiary treatment centres, had the lowest referral rates for oncological interventions, with Doncaster rates in between.

Breathlessness was recorded for 96% of patients in this study which is higher than 78% previously reported in mesothelioma (Higgs and Newbury, 1999) and the 78% and 80% reported in studies of patients with lung cancer (Edmonds *et al*, 2001, Krishnasamy *et al*, 2001).

Pain was recorded as affecting 91% of patients. Although 85% of the patients in this records survey had been prescribed opiates, the doses of morphine appear to be surprisingly low: the *median* equivalent 24-hour dose of oral morphine was 100 mg. Validated pain assessment tools were not found in any of the medical records and yet there is evidence to show that these can be used to tailor treatment more effectively (De Conno and Martini, 2001) Nevertheless, on further examination of the notes it became apparent that the median doses of oral morphine equivalents were misleading: 12 patients (15%) appear to have had pain that required multiple combined approaches to analgesia, suggesting complex pain. In view of the problems of accessing data from medical records, and studies suggesting inadequate pain relief in cancer patients, it is likely that 15% is an underestimate of the percentage of patients who may need specialist advice regarding analgesia. A large survey of hospice patients, who might be supposed to represent the more symptomatic patients, described 12.14% of opiate-treated cancer patients as receiving high dose morphine, defined as >300mg oral morphine equivalent/day (Bercovitch *et al*,1999).

The medical records survey revealed that psycho-emotional symptoms were recorded for 46% of patients. A review of 46 patients with mesothelioma cared for by a palliative care service found that 68% had psychosocial issues (Higgs

and Newbury, 1999). These percentages are considerably higher than have been reported in lung cancer (Sarna, 1998:342). This builds on previous work suggesting that patients with lung cancer suffer the greatest psychosocial distress (Zabora *et al*, 2001; Sarna, 1998). Chapman *et al* (2005) suggest that these factors must be addressed in pain management in mesothelioma.

Diagnosis of mesothelioma was confirmed during life in 63 of 80 patients and strongly suspected in at least a further two cases. The records failed to show whether or not 23 of the 63 patients had been informed of their diagnosis although good practice guidelines state the importance of recording this information, including any decision not to inform a patient of their diagnosis, with reasons for this decision (Brennan, 2004:353-4). In mesothelioma, given the specific medico-legal issues, it is particularly important that this guidance is followed. Almost a third of patients were informed of the diagnosis by a junior doctor, this raises some questions, given that the diagnosis is particularly distressing for patients in the absence of effective treatments, and the need for the patient to have confidence in the medical staff (Brennan, 2004: 330).

In the UK, men visit their GP three times a year on average, although this rises with age (National Statistics, 2006). The high consultation rate, 10 in the last year of life, for patients with mesothelioma, confirms the high disease burden and also the central role of primary care in the care of the dying. Leeds patients appeared to receive more consultations and proportionately more visits than the other two sites but the significance of this is unclear. Two or three hospital admissions in the last year of life or from disease onset represent considerable disease burden and patients were not necessarily always admitted to the same hospital. Day Unit admissions added further to the disease burden. The majority of these admissions were due to recurrent pleural effusions and may have been prevented by earlier referral for pleurodesis.

In spite of the high symptom burden, short survival time and lack of effective disease-modifying or curative treatments, just under half of the 80 patients were referred to palliative medicine. In common with previous studies in patients with cancer, these referrals were made when the disease was advanced (Morita *et al*, 2005). Hospices provided services to a third of the 80 patients, a high proportion for any disease group (Eve and Higginson, 2000). Most admissions

occurred when the patient was close to death, and most hospice patients died in the hospice, suggesting that referrals to hospice/palliative services were late.

Most of the patients with mesothelioma (75%) had significant co-existing illnesses, some of which were smoking-related. The smoking data reflect social trends and are relevant because smoking and asbestos exposure are co-carcinogens for adenocarcinoma of the lung. Smoking does not increase the risk of mesothelioma in asbestos-exposed workers.

Survival from first presentation to medical services, 294 days (9.7 months), agrees with previous UK studies that give a range from 7 to 14 months. If the median interval of 36 days between symptom onset and presentation to medical services is added, survival from symptom onset increases to almost 11 months.

Studies suggest that around 50% of people with cancer wish to die at home and around 25% achieve this (Dunlop et al, 1998; Townsend et al, 1990) In this study, only 14% of the patients with mesothelioma died at home. A high percentage, 30%, died in a hospice in contrast to just 8% of cancer patients in general (Eve and Higginson, 2000). The availability of two relatively large, well-established hospices in Leeds may explain the higher proportion of hospice deaths there, due to easy access. Although 61% died peacefully it is concerning that 21% experienced distress lasting more than an hour before they died.

The following chapter investigates the patients' experience of mesothelioma and reports the findings from interviews with patients.

# Chapter 4: Living with mesothelioma:

## Interviews with patients

Semi-structured interviews were conducted with 15 patients, (m=13, f=2, mean age 69 years), who had malignant pleural mesothelioma, in order to reach an understanding of the lived experience and meaning of their situation. All the interviews took place in the patients' homes in northern England, except for one, with a man who was interviewed in a hospice; in twelve out of the fourteen patients who were married or co-habiting, their spouse or partner was present. Two patients were interviewed in the week before they died. The patients knew that I was a GP and hospice doctor with a particular interest in their illness and the effects it was having on them and their families. I attempted to put patients and their spouses/family carers at ease and conducted the interviews in the role of an informed and interested friend who was also a doctor. From my perspective, most interviews rapidly settled into the familiar, relatively informal nature of a GP consultation but with everyone aware that I was not there as a family doctor (p84)

The findings from the interview data are presented to give a picture of the patients' experience of the disease and the meaning it had for them and their families. This report illustrates the chronological nature of the accounts given during the interviews: participants were invited to start by describing their work history and exposure to asbestos and then to recount the story of their illness from symptom onset, using an interview guide as a prompt (See Appendix 4). Themes reported under each subheading are illustrated by quotes in boxes at the end of each section. Key points are summarised at the end of the relevant subchapter.

## 4.1 Asbestos exposure and hazards advice

### *Occupational exposure*

*'...wrapping copper piping with asbestos cloth'*

All 15 patients reported that they were aware that they had been exposed to asbestos; 12 men recalled their exposure had occurred at work, which was related to the nature of the industry in which they were employed (see Box 4.1 and Table 4.1). The patients interviewed had mainly been employed in those industries that were responsible for the majority of occupation-related cases to date: shipbuilding, railways maintenance and the power industries. The interviews described the dirty and dangerous working environments in which asbestos exposure occurred.

### *Para-occupational or bystander exposure to asbestos*

The two women patients who participated in the study had non-occupational routes of exposure to asbestos. One woman, Mrs N, had washed the overalls of her husband and son who had both worked in the shipyard although she preferred to believe that she had been exposed to asbestos from the dilapidated market hall where she had worked. The other woman, Mrs T, believed she had been exposed to asbestos when an asbestos-roofed building next door to her house was demolished without any safety precautions. Environmental contamination with asbestos accounted for the exposure of one patient, Mr Q, who had lived close to the notorious asbestos textile factory in Armley, Leeds, during his childhood. His illness developed 60 years later.

### *Multiple exposures to asbestos*

Six of the fifteen patients recalled being exposed to asbestos in more than one situation. These included four men who had been employed in up to three high-risk occupations and two patients with mesothelioma whose fathers, both shipyard workers, had died from either asbestosis or mesothelioma. Two patients mentioned their concerns about other family members currently working in occupations that had previously been associated with asbestos exposure.

#### **Box 4.1: Exposure to asbestos**

*Mr H: 'I spent all through my apprenticeship working on them, and wrapping copper piping with asbestos cloth, about, nearly, some of it, 5/16, 3/8 and about 2in wide, and you're wrapping it round (pipes) and getting all the bits off it ...they used to dump the rubbish at the plant down one part of (the yard), and people used to (play) snowballs with it.'*

*Mrs N: 'They both worked in the shipyard and he worked on the Subs, didn't you? Well you used to wash their overalls, didn't you?'*

*Mrs N: 'I worked there all them years and that's why I think I got it on the market...It was all over – in the roofs and that, well I worked on a stall and you had to go upstairs to the stockrooms. The roof let it in and it was all dusty coming down...even then I didn't think about what it was'*

*Mrs T: '...about 1985 or '86, it was an asbestos roof like that building, the garage, and they came and demolished it...and all they did was just smash all the asbestos off, they didn't do it controlled as they should have done.'*

*Mr T: 'I can remember coming home from work one day and (wife) had got a bucket of water and was washing the sills off this big window with this grey dust that she'd been covered in...and they smashed it [the building] so the whole cement and the fibre content had been swirling around...'*

Pt ID	Age	m/f	Exposure at work	Occupation	Industry	Para-occupational exposure	Bystander exposure
Mrs N	72	f	No	Market stallholder	Retail trade	Son and husband's work-clothes	? asbestos in market ceiling
Mr D	62	m	Yes	Cabin lad/shunter	Railway maintenance	No	No
Mr M		m	Yes	Labourer	Shipbuilding	No	No
Mr J	66	m	Yes	Apprentice millwright	" "	No	No
Mr U	68	m	Yes Yes	Sheet metal worker	Shipbuilding 5 yrs then Insulation firm 4 yrs	No	No
Mr I	61	m	Yes Yes	Engineering apprentice 9/12 Engineering foreman 23 yrs	Shipyards Paper mill	No	No
Mr K	72	m	Yes	Shipyards worker	Shipbuilding	No	No
Mr Y	75	m	Yes Yes	Marine engineer 4 years Maintenance engineer >10years	Shipbuilding Railway then gasworks maintenance	No	No
Mr S	58	m	No	Store manager	Retail	No	Fireproof ceiling was replaced in the store
Mr C	66	m	Yes	Maintenance engineer	Manufacturing	No	
Mr T	79	m	Yes	Labourer	Missing data	No	
Mr Q	81			Floor layer (asbestos tiles)	Construction		Lived near asbestos factory
Mr V	68	m	Yes	Welder	Power station construction	No	No
Mr H	81	m	Yes	Lagger	Railways maintenance	No	No
Mrs T	55	f	No	Housewife/ Shop assistant	Retail	No	?Demolition of asbestos shed next door

**Table 4.1: Details of sample and asbestos exposure – patient interviews**

### *Asbestos hazards advice*

Most of the interviewees reported that they had not appreciated the dangers of working with asbestos during their years of employment. Nine of the twelve men who worked with asbestos could not recall being given any Health and Safety advice regarding asbestos hazards during their time at work. In the three cases who had recalled being informed of the hazards associated with asbestos, only one man acted upon the advice. One patient, Mr U, recalled warnings concerning *blue* asbestos whilst he was working for an insulation company in Australia but he had discounted it at the time because he was working with

*white* asbestos. Mr I, who had been an engineering foreman in a paper mill, recalled receiving Health and Safety paperwork regarding asbestos but had not appreciated its significance at the time; in the interview he hinted at both personal guilt and managerial neglect. In just one case, that of Mr V, hazards advice had been taken seriously and acted upon. Although he admitted initially ignoring the hazards warnings, following more information in the 1970s, Mr V left his job at a power station and moved to the relatively safer environment of a coal mine. However, by that time he had received sufficient exposure to asbestos to result in mesothelioma many years later. Ironically, Mr V, who had changed jobs to avoid asbestos, and whose wife had developed pleural plaques, presumably from washing his clothes, was diagnosed as a result of a screening x-ray when he was asymptomatic. The annual x-rays were originally suggested by his GP in 1994 when his wife was found to have pleural plaques (presumed to be due to washing her husband's work clothes). Mr V was also found to have pleural plaques on his initial x-ray in 1994; seven years later new signs developed which were then proved to be mesothelioma.

### *Anticipatory anxiety: the 'Damocles syndrome'<sup>29</sup>*

Mr U, although appearing to discount asbestos hazards advice at the time because they related to blue rather than white asbestos, had subsequently heard of workmates who had died due to mesothelioma. In later years this alerted him to his own risk of developing mesothelioma. When he suffered persisting pain following a minor injury it prompted him to ask for a chest x-ray because he suspected the diagnosis of mesothelioma at that time. Similarly, Mr V and his wife reflected that they had been worried about the risk of mesothelioma for many years, particularly as they also learnt of former workmates dying from mesothelioma. As well as the anxiety pre-diagnosis around the risk of mesothelioma, anticipatory anxiety post-diagnosis reflected concerns about severe pain and breathing difficulties based on media or other indirect accounts of patients' suffering. Anxiety about the risk of asbestos-related disease appeared to extend to consideration of other family members once a diagnosis had been made. This led to a sense of constant alert, particularly regarding the younger generation (see Box 4.2).

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<sup>29</sup> The 'Damocles syndrome' was first described as anticipatory anxiety experienced by people at high risk of developing spino-cerebellar ataxia, a fatal genetic condition ( de Villiers 1997).



#### **Box 4.2: Asbestos hazard advice and anticipatory anxiety**

*HC: '...when did you first start hearing at work about asbestos as a health risk?*

*Mr V: 'Well I never really took much notice of it, it were never a big fear, I should say, until oh maybe late '70's, something like that, and for that reason I got out of the game, to be honest with you. I got a chance to get back at the Coal Board because I'd worked there before and I got a job on the surface, still as a welder, but away from all the muck and filth in the power station.'*

*Mr I: 'You were given lumps of bumph, you know, 'Read through that', that sort of thing, 'from a Health and Safety point of view', and left you to get on with it. So, if you didn't read it up, then it was your fault...it was down to you with no emphasis laid down, you know, main, look, these are the main priorities, it should have been a proper seminar, you know, training seminar on health and safety alone, which was of prime importance really.'*

*Mr U: 'I'd always been aware that I might have it because me friends around me were going one by one....'cos the lad I worked with, he only went in January.*

*HC: 'Were these workmates from the insulation work?'*

*Mr U: 'No, they were from the sheet metal shop....whole family wiped out, father, two sons'*

*Later in the interview:*

*Mr U: 'Well it started really thinking I had a disc out. I pulled a plug out over there and it didn't come. It pulled all the muscle in my arm and I thought I'd pulled a disc as well...So I went to the doctor...he said 'I think you've pulled a muscle'. I said Can you send me for an x-ray?'... I mean because my chiropracter was getting no nearer with it. So he sent me for an x-ray on my back and I said 'While I'm there will you get me one on my chest because I've worked with asbestos when I was in my 'teens, when I was in my twenties.'*

*Mrs V: 'We've got 4 children and we hope that they don't, in time, develop this.'*

*HC: 'How much of a worry is that for you?'*

*Mr V: 'Very much.'*

*Mrs V: 'It's a niggle all the time there, isn't it?...And every time we got a cough or a cold we used to think "Is this the start of it?" because we knew his friends who'd developed it and died from it.'*

*Mr V: 'Well we were working in it in the '50's, I knew one or two lads who were in the same thing as me and I know at least 3 who've died with mesothelioma.'*

### **Causation**

The lack of health and safety information whilst working with, or near, asbestos added to the difficulty in accepting asbestos as the cause for one patient, and caused emotional distress and anger. Two patients proposed alternative routes of exposure to those accepted by their medical and legal advisers: Mrs N wondered if her disease related to exposure to asbestos from the dilapidated indoor market that had been repaired while she worked there, rather than blaming the contaminated work clothes of her husband and son. Similarly, another patient, Mr D, questioned whether his illness had resulted from exposure due to working on railway carriages and wondered if asbestos in the air from the nearby shipyard had been to blame. Attribution of the disease to

asbestos exposure many years earlier caused some problems for patients who found it difficult to accept the long latency period, although duration of exposure was not an issue raised by these patients (see Box 4.3)..

#### **Box 4.3: Causation**

*Mr M: 'I'm angry 'cos I don't know where it's come from. I just haven't got a clue at all and that's what makes me feel more angry, where it comes from, where I've picked it up from. 'Cos nothing was ever said to you about asbestos at all.'*

*Mr D: 'It was only the water separated the shipyard from the railway yard....whether it was in the air I don't know.'*

*Mrs N: 'How many years does it take, more than 20? ... it's a long long time ago.'*

## **4.2 Coping with symptoms**

*'...my breathing was terrible'*

### *Becoming unwell*

The symptoms patients experienced at onset and as the disease progressed corresponded with previous accounts of mesothelioma, although not surprisingly, most of the participants did not have severe symptoms at the time of their interviews (Edwards *et al*, 2000; BTS, 2001; Yates *et al*, 1997), (see Table 4.2). Seven patients recalled that they initially went to their GP, or directly to the hospital, with shortness of breath, two with persisting chest pain; two with fatigue; two with chest infection and/or weight loss; one was asymptomatic and detected on annual chest X-ray. One man reported that he had injured his ribs in a fall and an X-ray performed to investigate persisting pain revealed pleural shadowing and prompted investigation. Symptoms were reported by the patients in terms of their impact on normal activities, particularly physical tasks around the home and hobbies. Patients had their own ideas about their initial symptoms, often attributing symptoms to getting older or working hard.

Patients redefined the meaning of their symptoms as the disease developed: initial 'benign' interpretations of symptoms altered as the patients developed a greater understanding of their illness. In some cases this knowledge appeared to empower the patients: they felt able to tell their doctors when pleural

effusions had recurred and expected appropriate intervention. However it also gave rise to anxieties as knowledge of the disease made it harder for patients to ignore or deny the symptoms that indicated disease progression.

Patient ID	Initial symptom	Pleural effusion	No of pleural taps	Pleuro-desis	RT*,CT, or surgery	Condition at interview
Mrs M	Dyspnoea	Yes	3	Y		Weak, thin, breathless
Mr D	Dyspnoea	Yes	4	Y		Breathless, low mood
Mr M	Dyspnoea	Yes	3	Y		Fatigued
Mr J	Weight loss, chest infection	No				Breathless, emotional
Mr U	Chest pain	No			Too ill for CT	Weak, nephrotic syndrome
Mr I	Dyspnoea & fatigue	Yes	3+	Y	RT	End-stage illness, dyspnoeic
Mr K	Dyspnoea	Yes				Fatigued
Mr Y	Severe chest pain	Yes	2	Y	CT	Low mood, breathless, tingling in arms
Mr S	Fatigue	Yes	3	Y		Breathless on exertion
Mr C	Dyspnoea	Yes				Close to death
Mr T	Dyspnoea	Yes				Emaciated, breathless
Mr Q	Dyspnoea	Yes	3	Y	RT	Frail, breathless
Mr V	No symptoms	Yes	1		RT	Breathless, chest pain
Mr H	Cough	Yes	2		RT CT	Fatigue, breathless, painful lump on chest
Mrs T	Short of breath	Yes	2	Y		Breathless on exertion, tired

**Table 4.2: Clinical features and interventions** (RT=radiotherapy, CT =chemotherapy)

Many patients appeared reluctant to seek help, even when suffering from very distressing symptoms. This was acknowledged by two of the interviewees, one of them (Mr I) blamed his own 'macho' attitude and he also admitted that symptoms, particularly pain in his case, caused considerable anxiety, Box 4.3. It was clear that most couples dealt with symptoms jointly and, in several cases, the male patients deferred to their wives with regard to calling for assistance with symptom management.

Virtually all the patients were concerned to assure me that they were making the best of a dire situation. The spouses, 11 wives and two husbands, gave the same impression as the patients, perhaps taking their lead from the patients: that they were coping, together, as best as they could in the circumstances. Patients appeared reluctant to enlarge on their feelings, perhaps as a strategy to avoid additional emotional distress for themselves and/or their relatives, and in the interviews their spouses backed them up. Relatives present in the interviews appeared to use a variety of strategies to limit emotional distress (this may have impacted on the data obtained from the interviews but had not been predicted in the study design and specifically excluding relatives from the interviews may well have reduced recruitment).

### *Fighting for breath*

Dyspnoea, the main symptom affecting most of the patients, was seen as a potential threat to life; patients and families expressed intense anxieties associated with it and their attempts to manage it. Fear was evident in the terms used such as 'fighting for breath' and 'gasping her last' and with reports of other people with mesothelioma, who they had known or learnt about in the media, who were said to have 'drowned in fluid' or 'suffocated to death'. Patients reported that they frequently continued to be breathless, although usually to a lesser degree after treatment such as pleurodesis which, when successful, stopped effusions recurring. Self-help breathlessness management techniques, proven to increase patients' sense of mastery over breathlessness, did not appear to have been taught to any of the interviewees (Bredin and Corner, 1999). Terrifying cough and breathlessness were reported as major problems for one couple, Mrs T, the patient, and her husband, Mr T. The extract from the interview with Mrs T also illustrates the impact on the patient's spouse and the efforts he was able to make, somewhat to his surprise, to help her. As in many

of the interviews, this patient's spouse was at pains to assure me (and himself) that they were coping but it was clear from the interview that Mr T felt solely responsible for managing this distressing episode (see Box 4.4, below).

### *Dealing with pain*

Pain was only reported as a major problem for one of the patients interviewed and this had largely responded to treatment by the time of the interview. Others described pain as 'discomfort' that was manageable with analgesics, although it appeared that a certain amount of pain was accepted by some as an inevitable consequence of having cancer. Reluctance to seek help was also accompanied by a reluctance to admit to the severity of the symptoms, as in Mr Y's refusal to admit to being an 'emergency' when clearly in great pain (Box 4.4).

#### **Box 4.4: Dealing with symptoms**

*Mrs T: 'Well, I get to the point where I cough and cough, get wind or want to burp, then I'm sick, and the last time I've been sick I've nearly choked. It's a good job Ian was there, I seem to lose my airways or whatever... it seems I want to clear my throat somehow, and the only way I can do it is by being sick.'*

*Mr T: 'It's like a thick, clear fluid that comes up, a sort of – not quite wallpaper paste but that sort of stuff... firstly you're not as strong, to be able to cough it up, and secondly it seems to block all your airways... at midnight last night we were both laid on the bathroom floor with C going (gasp) and absolutely panic stricken that that was her last breath, and I am trying to console her, trying to rescue her, and well there's been times when I wouldn't have been able to cope, but somehow I'm coping better than I ever thought. ...So we are coping.'* (patient Mrs T and her husband)

*Mr M: '...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 Y: '...about the first 2 or 3 days in April, good grief, violent pains and all this business in my chest. I had another day off, and that went away. Then a fortnight after that, I went down to work, did my usual bit of sweeping up and bit of cellar work, cleaning pipes and stuff like this, you know, and I came home at about 9 o'clock and - 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!" So we rang for the doctor. They asked if it was urgent, I said 'No', - the doctor arrived after his surgery in about an hour. He arrived, examined me, gave me a severe chastising for not getting him here earlier. I said I didn't think it was urgent. "I'll be the judge of that" he said, and rang for an ambulance.'*

*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.'*

*Mr I: 'A lot of it's my own problem. Too macho to be shouting out when I should be, you know, when I'm in pain. I'm silly and I'll say, look, look, what you give me, just stop this bloody pain will you? You know, because personality change is quite enormous when I'm in pain. It's terrible, you know it's, it's because it also brings on the anxiety side of it which makes the pain worse.'*

## *The erratic disease trajectory*

*'Do we have 12 weeks where you can still walk around? We just don't know'*

The unpredictable and often rapid onset of pleural effusions caused great distress, compromised patients' abilities to manage their illness and disrupted their 'treatment calendars' (Costain Schou and Hewison, 1999:122-3). Pleural effusions tended to recur at short intervals in many patients, necessitating emergency hospital admissions for pleural aspiration. This was usually followed by referral to thoracic surgery units, often in different hospitals, for pleurodesis to be performed (see Table 4.2, p138).

Alongside acute episodes of breathlessness and pain, patients reported that steady, sometimes rapid, decline in function was also common. Loss of appetite and weight, reduced mobility, general frailty and confusion were also raised as common symptoms. Mr Q had fallen on the day before the interview and hit his head; his wife was worried that this may have increased his confusion. The uncertainty of the progress of the disease also caused anxiety: patients and relatives struggled with not knowing the significance of symptoms and whether or not their condition was stable; even when they felt reasonably well, they revealed background awareness that the disease would be fatal (see Box 4.5).

### **Box 4.5: Disease progression**

*Mr S: 'If you could call it stable, it's stable. Or if it's creeping on I don't know about it. I suppose it will creep on eventually won't it?' (patient Mr S)*

*Mr T: 'But within 6 weeks you can't walk round town and now we're sort of 12 weeks into it...you are progressively getting worse, I just don't know the speed of what's coming over you, or the stages of it... do we have 12 weeks where you can still walk around the house then 12 weeks in bed? We just don't know.'*

*Mrs T: 'And nobody knows, no one can answer that, can they? It depends how I react to treatment, if I get any.' (patient Mrs T and her husband)*

*HC: 'And so what are your main problems at the moment?'*

*Mr Q: 'Well I'm not eating, for a start, but I put that down to not walking about, I can't get out because it's been cold weather...I've no appetite... I'm all right in myself.'*

*HC: 'Has it slowed you down?'*

*Mr Q: 'Oh yes, I can't do anything...I'm jiggered if I try and do anything.'*

*HC: 'What about concentration and memory and things like that?'*

*'Well I'm beginning to wonder today, after doing...'*

*Mrs Q: 'We've been an hour taking £26 from £303! (laughs) He wouldn't believe me, in fact his daughter rang up and she had to tell him.'*

## 4.3 Investigations and interventions

*‘They called it keyhole surgery but I was scarred like hell!’*

Most patients were referred for a chest X-ray at their first or second GP consultation, one of these at the patient’s request (Mr U). After the abnormal chest x-ray, patients were seen quickly by a hospital consultant, in most cases within a few days, two weeks at the most. Patients’ experiences varied considerably: for most patients the investigations and/or interventions were unpleasant and distressing to a variable degree; others seemed to tolerate the procedures well.

### *Managing pleural effusions*

Twelve patients reported that they each required several pleural aspirations, 8 of these had also had pleurodesis, (Table 4.2). Patients seemed to understand the concept of ‘fluid on the lung’, possibly because for these evidently practical men, (and also the two women), this was perceived as amendable to a practical technique that gave rapid results. However they also revealed that not all these procedures had been straightforward and complications such as ‘shock’ and tumour tracking along thoracoscopy ports had occurred. Three patients reflected concerns that the procedures that they were undergoing appeared to be being taught to junior doctors, Box 4.6. One patient, Mr M, was an exception: he appeared to have enjoyed his hospital stay in which VATS biopsy and pleurodesis were performed, partly because the investigations were not distressing and he had also enjoyed the camaraderie on the cardio-thoracic surgery unit.

#### **Box 4.6: Investigations and interventions**

*Mr I: 'It was a terrible ordeal. No pain, no...but it's the weirdest experience. He said this will happen to one say, one in a hundred...I was practically in shock. Only took about 500mls...and I was going 'Oh God, I feel as though I'm dying' He (consultant) walked in and said 'You'd better stop now...can't you see that he's close to going into shock' Soon as the needle came out I was alright.'*

*Mrs N: '...they drained the fluid off...after a fortnight I said to him 'It's back again'. So after that he took me in again...put a big tube in my back and they puffed stuff in to seal it up...that stuff they put inside you gives you flu-like symptoms...I was ill for 24 hours. All I wanted to do was get out of hospital and come home... And that was a mess, the biopsy, and I started coming out in big lumps. They said it's tracking from putting the tubes in.'*

*Mr M: 'I didn't even know they'd done it to tell the truth, the anaesthetist knocked us out....when I came to I was in a different ward. I felt really great when I came out of there. In fact I enjoyed it in there, there was a lot of people in there getting 5 multiple bypasses!'(Mr M talking about surgical pleurodesis)*

*Mr S: '...they were going to do a biopsy... they said it would be sort of keyhole surgery so it didn't bother me too much so long as I was asleep (laughs)...the drain again was put on my lung in another area. This was a long stay, 11 days...They called it keyhole surgery but I was scarred like hell (laughing) then the drainage had to take place again ...and they left me with a little bag. They said "We're not taking that bag off you, you're still mobile, just be careful how you sleep" I had to devise a contraption where I could hang it!'*

*Mr J: '...the bloke seemed to be teaching the lass how to do it [biopsy].'*

*Mr T: 'The gentleman, we don't know his name, who came to do the talc...'*

*Mrs T: '...and he came in an all green gown into the nurse station and said he'd got to do this talcum powder thing, and the matron said "Yes, have you done it before?" He said "I've never done this before".'*

*Mr T: So he laid (wife) on her side and poured in some liquid anaesthetic, kept the tube nice and wet and then tried to put a dry powder down it, and it just all clogged, it just did not seem to work and we were convinced it hadn't worked...we thought "Yes, I don't think you have done that before!"*

*Mr S: 'Yes, I get discomfort from this pleurodesis...which I've had ever since they did it, but it's not out and out pain, it's just occasionally you know it's there.'*

### **Radiotherapy, chemotherapy and surgery**

Five of the 15 patients reported receiving oncological treatments: two patients had radical surgery with radiotherapy; one of these had adjuvant chemotherapy as part of a clinical trial; another patient had chemotherapy alone in a clinical trial; two other patients received prophylactic radiotherapy to port sites. One patient recalled that he was unable to have prophylactic radiotherapy because he had developed nephrotic syndrome that required in-patient hospice treatment. Radiotherapy alone did not seem to cause distress, although the distance of 70 miles to the nearest centre had initially deterred one patient in



Barrow, Mrs N. However, when she did have radiotherapy it failed to prevent the subsequent development of chest wall invasion due to tumour tracking along port sites. In contrast to patients who reported their straightforward experiences of radiotherapy, the two patients also receiving chemotherapy as part of clinical trials recalled a considerable treatment burden both in terms of the practical demands of multiple hospital appointments and the side effects of the treatments.

Radical surgery appeared to cause particular concerns for patients and their families. The two patients who had radical surgery, Mr V and Mr H, had both been made aware that it was unlikely to be curative. Mr V, who had been operated on just three months prior to the interview, was doing well and hoping for an extended survival. The other patient, Mr H, had developed a lump on his chest wall that was found to be a recurrence of the tumour; he was then offered chemotherapy in a clinical trial. Both men who had undergone surgery were particularly well-informed about their illness, treatment and prognosis. In both cases they had extremely supportive wives who had also learnt as much as they could about the illness but their relationships with their specialists was different.

For one couple, Mr and Mrs V, their expectations of multi-modular treatment, gleaned by them from North American websites via the Internet, were not realised and they were not happy with the explanation given by the consultant, causing dissatisfaction and anxiety. The lack of choice of type of treatment in a randomised controlled trial was also highlighted by this patient's wife, a practice nurse. She voiced more anxieties than her husband in the interview, In the second case, a more easy, trusting and mutually respectful relationship with the consultant was reported: both patient and doctor used humour, presumably as one way of reducing emotional tension in consultations when bad news and confirmation of dreaded fears were present. This patient, Mr H, whose worst fears were realised when his tumour recurred after radical surgery, was then offered chemotherapy – he recalled being anxious when asked to choose whether or not to undertake this treatment as part of a clinical trial. In addition, uncertainties concerning access to treatments and effectiveness of treatments caused further anxiety (see Box 4.7).

#### **Box 4.7: Radiotherapy, chemotherapy and surgery**

*Mr J: '...she said we'll take you in and bombard this with radiotherapy. So I went and had that done, but it didn't seem to give me much trouble'*

*Mr Y: 'I've had 3 days at radiotherapy and 12 sessions of chemotherapy. I've seen the doctor, is it 3 or 4 times? I saw the consultant first and since then ...'*

*Mrs Y: ...once since when he got you to decide to go on the trial.'*

*Mr Y: 'Yes, I saw him once in [hospital] and then they transferred me from Dr A to Dr B and he got me to go on to this trial thing they're running, and I've been about 12 courses of this...and so far so good....That's the full course and I've to go for a scan, the time tunnel thing... where you go down and they stick this gunge in your hand and make you burn all over and all this business... in about a month... then see the doctor again.'*

*Mrs V: 'The only thing that bothered us was, Mr C the surgeon referred him to the oncologist with a view to multimodular treatment. Well he didn't have the multimodular treatment, he just had the radiotherapy and it wasn't the correct amount because of the liver, and he didn't have the chemo. The oncologist wasn't in favour of that, so we've had to go along with that. I did question him and you don't like questioning the specialist do you? But I did say "Is there any more?" In the nicest possible way of course, you don't want to tread on peoples' toes. But he said it would compromise the radiotherapy, and also there was nothing there to measure if he gave the chemotherapy. But people don't have anything to measure if they have breast cancer or bowel cancer, but he said it was different from those cancers.'*

*Mr V: 'I could see his point really, how he explained it to me. I mean obviously I was satisfied with the, because to me, as far as I was concerned, they'd cut out the infected lung before it had really got bad, and well in my mind, you know the way I was at the time, and they'd cut that out, and all I was bothered about was, my impression was that they were giving me this treatment as like an aftercare sort of thing, not to kill anything off. It was just all the surrounding area, to make sure anything it had been in contact with or anything like that.'*  
*(Mr V and his wife, Mrs V, who had looked up mesothelioma on the Internet)*

*Mr H: 'So when I went back to see him he told me that the cancer had, like, come back, and he says "I'm sending you straight down now to Dr H" because I was to see H one time, and V for check-ups. So I went straight down to Dr H and he says 'I'd like you to go on this 12-15 week trial", so I says "Well I've no option, have I, really?" He says "Even if you didn't go on it you'd still get treatment" but I says "Yes, I'll go on it.''*

*HC: 'What sort of treatment was that?'*

*Mr H: 'Radiotherapy.'*

*Mrs H: 'Well it was a trial, wasn't it, there was three choices but you couldn't choose which, two was different chemotherapy and you got chosen for radiotherapy.'*  
*(patient Mr H and his wife)*

## **4.4 Finding out about mesothelioma**

*'I just turned to wood, stone, whatever, I was numbed'*

It was a criterion for recruitment into the study that the patient knew the diagnosis of mesothelioma. From the interviews, it was clear that all the patients had been told that there was no possibility of cure. Even in the two patients who

presented with early disease and then had surgery, it had not been suggested that this offered a cure (Box 4.8).

Most patients recalled that they were informed of the diagnosis by the respiratory consultant, one was informed by his GP. The short prognosis and lack of curative treatment were made explicit when the diagnosis was explained in every case. The patients confirmed that the status of mesothelioma as a prescribed industrial disease and the associated State benefits and civil claims procedures had usually been mentioned at the time of diagnosis. Only one of the fifteen patients seemed to question the doctor about the diagnosis or ask for further information, although several expressed problems with acceptance, especially regarding causation, in the interviews.

Many patients recalled being unable to take in anything else at the time of learning the diagnosis; not surprisingly several accompanying spouses recalled more details of the consultation than patients. Most patients felt strongly that they should be informed of the diagnosis when their spouses were present but in two cases their wives had been told before the patients. In both these cases, the patients were critical of this practice but for different reasons: one man wanted to have control of the information and hinted that he may have chosen to withhold the diagnosis from his wife, at least initially, the other man and his wife wished that they had been together when the diagnosis was disclosed. An apparent breakdown in communication caused anxiety for one patient when a nurse telephoned him, expecting that he already knew the diagnosis.

The patients' recalled their immediate reactions to the diagnosis: in most cases these appeared to occur in either of two forms, shock or stoical acceptance. The shock of the diagnosis was evident in the single word '*devastated*' that one man used to describe his reaction to the diagnosis. He was only six days away from death and just raised his head to whisper this single word (see Vignette 4.2, Mr C, p163). This was all that Mr C was able to utter apart from asking me to '*talk to the wife*' when I arrived. Some patients recalled that doctors had been kind and sympathetic when explaining the diagnosis but the overriding recollection was of a hopeless message: mesothelioma was an incurable disease for which no treatments were offered in most cases (Boxes 4.8, 4.9).

#### **Box 4.8: Learning the diagnosis**

*Mrs N: 'They said there was no cure for it, to take them lumps off... I could have radiology? Well he just said he were sorry and that we'd be able to go ahead and get a solicitor...'*

*Mr M: 'and he said 'I'm afraid there's no cure for it'...and my doctor says, 'It might be a while yet, it'll give you time to get things sorted out, you know'' (patient Mr M)*

*Mr Y: 'I had my wife and daughter with me...I just turned to wood. The doctor said "you've got mesothelioma" and I can't remember anything after that'.*

*Mrs Y: 'She said "It's mesothelioma, it's malignant, it's terminal and there's no treatment". They wouldn't take the lung out because it was too big an operation that would only give him another 6 months'.*

*Mr Y: 'I just went like that, I just turned to wood, stone, whatever, I was numbed.'*

*Mr J: 'To tell you the truth, when he first told me, my mind just went bonk. Shock....I can remember him being quite pleasant about it...he did it in a nice way, er, as soon as he mentioned what it was I knew...because of father. Definitely that was the worst day.' (Mr J's father died due to mesothelioma)*

*Mrs T: 'Yes, and I just says to him "Can you give me a time?" sort of thing, and he just says "No, I don't want to give you any false hope, I can't give you much hope"... They'd found these abnormal parts on my lung and he says "It's a type that doesn't respond to treatment"'.  
Mr T: 'He said "It's very very serious and it's in a position where we don't think we can help you".' (after protracted investigations eventually confirmed mesothelioma)*

*Mr T: 'He said "It's very very serious and it's in a position where we don't think we can help you".' (after protracted investigations eventually confirmed mesothelioma)*

*Mr U: 'I looked at her face and said 'You know something I don't, they've found cancer, haven't they?' She just broke down. So we went back to the doctor and he said 'Well I'm sorry you've got cancer of the lung'...It wasn't a good way of doing it but, on the other score, she got to know, or I wouldn't have told her. And that's the thing that annoyed me, I could have told her but I didn't have the chance, she had to tell me'*

*Mr I: 'So he had already spoken to the wife that morning, so she knew, so she was present when he came to give me the good news, mm, so he just came and told me what it was. He said 'I've told your wife that you need to get your finances sorted out, get your house in order and for the future, you know. Have you got anything to ask me?' 'No' I said, 'I can't think of anything.'(patient Mr I)*

*Mr S: 'Oh yes, I thought "Well there is a problem, a hell of a problem, she wouldn't ring out of the blue, would she? She rang me assuming that Dr P had given me the story...I'd got an idea, I was getting worried...you think the worst... "Are they going to be taking my lung out? Cut a tumour out?' Because I didn't know what the hell mesothelioma was...I'd heard about a lot of cases in Leeds and I'd read about people in the factories.'*

#### **4.5 Psychological reactions**

*'Sod it, I'll just take each day as it comes.'*

##### *Facing death*

Prior knowledge of workmates or family members with mesothelioma gave rise to anticipatory anxiety of developing the disease, echoing the so-called

'Damocles syndrome' (de Villiers, 1997, p28). After the initial shock of the diagnosis all the patients displayed an apparently unquestioning acceptance of the diagnosis of mesothelioma, although, as reported earlier, they sometimes questioned the way in which they had been exposed to asbestos. Most expressed their determination to cope as well as possible with support from their close family. In many cases it appeared that patients and families had negotiated an agreed way of coping with the illness and that this 'framed' their accounts. Patients often balanced their accounts of their knowledge that the disease was incurable with descriptions of how they would attempt to stay as healthy as possible (See Box 4.9).

Following diagnosis, most patients did not look for further information, one patient, Mr R, reflected that searching for further information could cause more problems, particularly as he accepted that he had a fatal disease (see Box 4.9). Two exceptions were the wives of the two post-surgical patients: they had actively explored a variety of sources including the Internet (Mrs V, Box 4.7)

In spite of the particularly dire prognosis, it appeared that most patients still managed to reframe their expectations of life, often exhibited hope and humour, and were at pains to emphasise to me that they were coping, albeit with some admission that emotions surfaced at times. This was a noticeable feature of many of the interviews and it appeared that the married couples had agreed that this was how they would face the illness, and its consequences, together. Two patients mentioned feeling angry in the interviews but the majority exhibited what might be perceived as a 'stiff upper lip' attitude and a fatalistic outlook. Several of the male patients did disclose emotional distress but this appeared to be minimised in the interviews and they reported that their emphasis was on making the best use of the time left. Some patients expressed hope of living much longer than anticipated but at the same time appeared to recognise that this was unrealistic. The age of the patient sometimes affected the way that they reacted to facing death: whilst older patients tended to be accepting of a terminal illness, the younger woman, 55-year old Mrs T, described ruminating over her situation and described how she attempted to view her situation from different perspectives as a way of trying to come to terms with it, Box 4.9.

#### **Box 4.9: Reactions to the diagnosis**

*Mr J: 'Oh yeah, I realise how bad me father got, so I'm expecting the same. How I'll handle it when it does arrive, I don't know... I don't want to know really, till it arrives, sod it...I don't know. They've never drained it yet. How I'll cope with it I don't know...It makes you feel angry 'cos I don't know if it's them that's caused it but somebody should be responsible for it, because I don't know what's caused it'*

*Mr M: 'it took me by surprise like, but I couldn't do owt about it so you've just got to accept it'*

*Mrs T: '... it's just it is continually on your mind when you're sat thinking, you think "Why me?" and then you think "Well why not me?" As you say, 1 in 3 people have got it so why not me? I've been perfectly healthy up to 55 so I've had 55, a lot of people don't get that long. That's the only thing that goes through your mind.'*

*Mr J: 'I'm not just going to carry on, I'm going to crack on. Well what we're going to do is to enjoy each day.'*

*Mrs J: 'It's a waste of time getting upset'*

*Mr J: 'Aye, a waste of time...I've had my upsets, I've had my tears...and after that I just said 'Sod it, I'll just take each day as it comes. I even go back to work once a fortnight. We both go don't we?'*

*Mr R: '...they said I'd be upset, and I was, I was a bit weepy every time... I kept it to myself for 3 months, I never told my family, just told my good lady who lives here, but eventually the doctor changed the sick note, didn't he?...from "thoracic haemorrhage" he put "mesothelioma" on the sick note...I slowly started telling friends, relations. But you start talking about it and you burst into tears, so... (laughing) but I think I've got over that. It said on one of the leaflets that the nurse specialist gave me...for 6 months you will be upset or about 6 months, and you resign yourself to the fact that you've got it and try and carry on as best you can...I try and occupy myself, make sure I go out every day if I can...I try, doing what I can, I've got to keep my heart going if nothing else...and deep breathing, away from the traffic (laughs).'*

*Mr I: 'Well I dealt with it very well actually. I weren't going to let it get on top of me and that's why I was kind of joking all the time and putting on a false front which I still do even though I do think about it at times. ...I just get on with my life and looking forward to the future...In eight years I've got my 50th wedding anniversary and I'm going to it, that's my goal at least.'*

*Mr R: 'I know it's bad so I think a little knowledge can be dangerous. If there's something to be done again, well, let the people who know what they're doing do it.....I mean you can drive yourself bonkers, you know, looking up this that and the other. I know it's bad, ...I know it'll never get cured.'*

### **Getting organised**

Some patients took a very practical approach towards facing death (See Box 4.10). The 55 year-old woman, Mrs T, although constantly thinking about her situation, had also been very practical and had spent time with her husband sorting through her possessions and deciding how they should be distributed. A self-help book had advised her that the act of making organised plans for after

death may help her to gain some sense of mastery over uncontrolled events, and she had decided to follow this advice. The other woman patient, 72 year-old Mrs N, clearly and unemotionally displayed a fatalistic view and seemed particularly accepting of the terminal nature of her illness. She knew that her husband could cook for himself and keep the house tidy as he had taken over these roles since her illness, having been taught by her. Patients sometimes had concerns about their responsibilities for their families: the oldest man interviewed, Mr Q aged 81 years, was the main carer for his wife whose memory was deteriorating. He had given thought to where he would like to be cared for when dying if unable to be at home and he based this decision on his past experience and realisation that his wife would not be able to look after him.

The two woman participants took an essentially practical approach to dealing with their own death. Several of the men spoke of the emotional turmoil that they were experiencing and in particular their distress at being unable to continue to do the practical tasks that fell into the pattern of the traditional male 'head of the household'. In contrast to the women who were interviewed, few of the men spoke openly about death or dying, veiled or oblique references were common and may have been a way of reducing emotional distress. However, in all cases, the men's accounts of anxiety, tears, rage and frustration were brief, and followed by further reassurance to me that they were coping well.

#### **Box 4.10: Getting organised**

*HC: ‘...but you mentioned about selling the car and trying to be prepared, how far have you gone with that? Or if you don’t want to discuss this that’s fine.*

*Mrs S: ‘No, well, we were sat last night, I have a jewellery collection, not expensive, A VERY large collection. Collectors’ pieces...and we were discussing it, I says “What do you think I should do with that?” We can’t think of anybody in the family who’d wear it...so I said “Shall we just leave it then, and when anything happens to you it’ll just go with the estate?” because we’ve no children...Or do we try and sell it?...And the clothes! I’ve got a couple of wardrobes of cruising clothes! I’m just saying “Shall I sort that out now and we’ll take it to the Cancer Research shop, or do you want me to leave it?” Anyway, my brother and sister-in-law have got totally opposite, they’re saying “Don’t sell your car yet, it’s too early...You might recover, they might have got it wrong” but no, we’re more practical than that, and it is positive thinking. Reading that book and everything, it does say you take control, do what you feel like yourself. We have always been practical, haven’t we?’*

*Mrs N: ‘How’ve I dealt with it? Well...I’m 72 years old and I’ve got to die sometime and I’ve got to die with something. I mean I could go out side and get knocked down and die, I could get the flu and die, so I’ve got this and I’m going to die, so what can I do? Especially living to 72...I think that it would upset me if I’d only been 30 or 40 but not now.’(patient Mrs N)*

*HC: ‘What about looking to the future, have you got any ideas about how you want things to be?’*

*Mr Q: ‘In the future? I’m just keeping my fingers crossed, hoping that (wife) is all right.’*

*HC: ‘You said you’d been quite practical about making plans.’*

*Mr Q: ‘We try our best. We’re not, shall I say, spendthrifts. We’re very careful really but I don’t know how she’ll go on on her own.’*

*HC: ‘It sounds like you’ve been caring for her quite a bit.’*

*Mr Q: ‘Well, for quite a long time, yes.’*

*HC: ‘What about avoiding hospital, would you mind going into hospital again?’*

*Mr Q: ‘Well, I’d prefer to be here but hospital doesn’t bother me. If I am ill, really ill, I’d like to go into a hospice...(Wife’s) dad went in when he was...he wouldn’t go in, he didn’t want to, but actually this nurse talked him into going in. Happiest he’d been in his life, he was.’*

### **Living with loss**

*‘There’s things I used to do I can’t do now...’*

The patients spoke with sadness about the loss of normal everyday functions due to their illness and described practical ways of dealing with these problems, often involving other family members taking on new roles. Many of the patients interviewed had enjoyed physical hobbies prior to being ill and had difficulty handing over practical tasks to others or having to relinquish activities such as gardening and dancing (see Box 4.11).

Loss of sexual function was mentioned by one patient, Mr D. Although I did not pursue the issue, it was clear that, behind the humour, this man was making



sure it was acknowledged that, for him, deterioration in sexual function was a significant matter. His wife was obviously embarrassed at this point and I felt it was inappropriate to attempt to explore the issue any further.

The patients described various ways in which they had made practical and psychological adjustments to the illness that could be construed as helping to preserve their sense of self in the face of the ultimate life crisis. Daily activities and outward appearance as well as future plans were major areas of adjustment and required a 'mental shift' in order to accommodate these changes, without succumbing to overwhelming stress.

Deterioration in bodily appearance caused great distress: two male patients showed photographs that portrayed them in previously good health, in marked contrast to their frail appearance at interview. One of the women, Mrs N, flapped her oversized blouse to demonstrate how much weight she had lost, obviously very distressed about her altered appearance. This patient showed more distress about her altered appearance than when talking about her impending death.

#### **Box 4.11: Psychosocial issues**

*Mrs H: 'Sport, he's lived for sport, haven't you?'*

*Mr H: 'I played football 'til I was 46, I played table tennis...Swimming'*

*Mrs H: 'Golf. Golf's been his life up till now, yes.'*

*Mr H: 'But I haven't been able to get out golfing.'*

*Mrs H: 'That's the worst part, he's usually been up at 6.20 in the morning...now it's 9.30 before he feels like stirring.'*

*HC: 'So it sounds as though this has had quite a drastic effect on your life.'*

*Mr H: 'Yes, what I've had to give up.'*

*Mrs H: 'Yes, social life as well, because we only ever did sequence dancing, that were our life, and we've no social life whatever now' (laughing)*

*Mr Q: 'I am really, but I get frustrated. I think "I'll do that little job, I'll move that" but I can't move it.' (patient Mr Q and his wife)*

*Mr D: 'There's things I used to do I can't do now..er, gardening the front, I can't turn that over. I don't cut the hedge, the wife cuts the hedge when we can get round to it, and, er, wash the car. I used to do a lot of jobs round the house, I can't now....do-it yourself – I can't do it now.' (patient Mr D)*

*Mr M: 'I can bend down but I've got to be careful. ...Like decorating, like we'd have done it-yeah, and that's another annoying thing – you can't do things....Gardens and allotment, we grew all our own fruit and veg, I couldn't dig, once I get down I'd have to stay down for a while. I'm short-tempered...And, like, I need more Viagra now! (patient Mr M- he and his wife then burst out laughing, his wife clearly embarrassed at this remark.)*

*Mrs N: 'I always had a good appetite, I loved my food and now I'm , just not hungry and I'm not eating. I don't like being thin, 'cos underneath I'm like skin and bone' (patient Mrs N)*

## 4.6 In it together – the effects on the family

*‘...everything should be shared with your wife... it’s a trouble shared.’*

All but two of the patients who were married or cohabiting were interviewed together (although not specified in the interview invitation) and there was a strong sense of previously good relationships being intensified and strengthened by the experience of the illness. Couples usually attended hospital appointments together and, as the patients' physical health deteriorated, the support of the spouse or partner was acknowledged.

Non-verbal clues demonstrated the deep relationships between couples: touching, smiles of encouragement, sitting close together. Some ‘rescue bids’ were evident when the interview touched very sensitive areas: Mrs M got up and found a tissue for her husband when his eyes filled with tears describing frustration over household tasks that he could no longer do; Mrs T’s husband decided we would stop for a tea break when his wife started talking about her prognosis. Patients described practical and emotional support from family members (Vignette 4.1, Mr V, p154). As reported earlier, the wives of both men who had undergone surgery had acted as information-gatherers and spokesmen for their husbands and seemed to have been more assertive than their husbands in dealings with consultants; both husbands appeared to be content with this situation and comforted by the obvious care.

Two male patients had no close family, one a recent widower, the other a bachelor, but they described help from friends and neighbours. Patients and family members also described protective mechanisms that they used to reduce distress to their loved ones. Relationship strains also surfaced or were possibly worsened by the stress of the situation; at times patients and their family members may have been at different stages of acceptance/awareness regarding the illness (Box 4.12).

#### **Vignette 4.1: Mr V – the story of his illness**

*Mr V served his engineering apprenticeship at the age of 17 years in Wakefield. After spells in the Army and a railway plant 'nothing to do with asbestos' he moved to a gasworks and where he had to repair and maintain the compressors. 'Everything was asbestos – the whole plant was asbestos.' He described drilling into asbestos sheets, bolting asbestos sheets onto steel frames to make screens and knocking asbestos lagging off pipes with a hammer 'Ignorance is bliss – well in those days we knew nothing at all about asbestos.' He had never been aware of asbestos risks at work*

*His illness presented with a nagging pain in his chest like a pulled muscle for a few days then suddenly became excruciating. His wife insisted on calling the GP who arranged instant admission. A large pleural effusion was drained on the day that he was admitted to hospital. After x-rays and scans, mesothelioma was diagnosed by biopsy – it was the first time he had ever had any significant illness. It came 'completely out of the blue' and he described being numb with shock. He could not recall the discussion of mesothelioma that the doctor had with him and his wife, although she could recall it word for word. He described going home and deciding the first thing he had to do was take his guns down to the police station so that they were not a problem for his wife to deal with (his firearms certificate was due for renewal the following month.) He decided who to leave some possessions to but felt unreal for about 6 weeks. Slowly he settled down and learnt to pace himself – he had been very fit and had loved walking. He then took up air weapons shooting but missed both walking and photography and rugby matches. During one outing to town he'd had a 'funny do' and so he was reluctant to go anywhere on his own and this had greatly curtailed his activities.*

*He agreed to take part in a clinical trial and had been suffering tingling in his hands and feet as a side effect of the treatment. Pain was not a big problem but seemed to be increasing – the interview was stopped while he remembered to take some paracetamol. Shortness of breath and fatigue were the main symptoms. He had been given the telephone number for the Mesothelioma help-line and a leaflet on mesothelioma but gave up reading after a few pages and had decided to take things 'day by day.' At the time of the interview he was having some bouts of low mood and relied on his wife to persuade him to get up out of bed and go to play snooker – he admitted how much he relied on her.*

*Although praising the treatment he'd had at the hospital he was disappointed that he had only seen the consultant once – he would have liked to have seen the consultant regularly. Likewise he had only seen his GP once since diagnosis. However his Macmillan nurse had been extremely supportive as had the District nurse, they had discussed his preferred place of care and recorded his choice of a particular hospice. The District nurse had also arranged a stair lift to help him up to his first floor maisonette.*

*The overwhelming impression was of a previously very fit man who was coping bravely and without fuss with a terminal illness. His approach to his illness was straightforward and practical – mirroring his working life - and supported by his loving family. He was interested in the study because he was pleased that someone was paying attention to what patients thought and hoped it would help patients in future.*

#### **Box 4.12: In it together**

*Mrs N: 'Oh yes, yes, he's upset about it – 'Don't talk about it mother', he says. I said 'You've got to (son), you've got to.' We've got a daughter as well- she came up last weekend and changed all my curtains...My daughter's more like what I am....'cos her husband died, died of cancer, so she knows like, what to expect.'*

*Mr J: '...I think me daughter's switched off. It's her way of handling it'  
(Describing help from son and son-in-law)Oh yeah, the son-in-law would (help) as well- but then there's waiting 'til he's got time to do it and then sitting there watching him do it...silly little things – he changed the tap.'(patient Mr J)*

*Mr U: 'I wouldn't have told her. I would have protected her 'til the time come, 'til I couldn't go on any further....but really, when you think about it, everything should be shared with your wife, because it's a trouble shared.'(patient Mr U)*

*Mr I: 'Oh the kids(grandchildren). ...drop in now and again you know... 'your grandad's not going to be here for such a long time....we're lucky... we're getting a bit more time than we thought ..we were going to have, so every opportunity is hands getting hold of you, they give you a hug and a kiss and a cuddle.'(patient Mr I –expressed hope that he would live 8 years to celebrate his golden wedding)*

*Mr J: 'I'll be off to ..see my sister in the next fortnight. I thought she had more sense but she got a bit over the top and I don't want to lose my temper, I've lost it enough.'(patient Mr J)*

*Mr I: 'She keeps saying 'Well what am I gonna do, what am I gonna have left to live on?' Sometimes I get a bit..er well, I say, 'Sod all, you'll have to work for a living.'(patient Mr I)*

### **Spoilt plans**

As well as the effects on daily routines the illness spoilt plans for the future: ideas about retirement and planned future together with their loved ones had to be painfully reconsidered. The uncertain disease trajectory added to distress and led to searching for meaning and certainty (see Box 4.13).

#### **Box 4.13: Spoilt plans**

*Mr T: '...we've always, every Saturday morning, gone down to Doncaster about 8.30 and trotted round town, we'd never use escalators, we were always first to the top of the stairs...and then suddenly really it's come on so quickly, hasn't it? We walk down to our gates, we like the wildlife and the flowers, but the small slope there creases you doesn't it? It really does take it out of you, getting dry after a shower or a bath, or even getting ready for bed.'*

*Mrs T: 'Yes, I have to sit down! (laughs) to recover.'*

*Mr T: 'So what I've got to try and find is, if I know that in February we were on holiday, and we've had the best holiday we've had for years, absolutely not a care in the world, then 4 weeks later you are breathless....It does seem strange that say, even in February when we were on holiday we had no inkling of this, going round the Caribbean, you can't believe...and we were climbing hills and all sorts, we were up and down the hilly areas, you'd no breathing problems at all.'*

*Mrs C: '...well it was supposed to be our retirement, we were going to do all sorts of things and then he got ill, just a year ago and it's been so quick, and now, well we can't do anything.'(Mrs C, wife of patient Mr C)*

## 4.7 Medication issues

*'...if one doesn't work take two...'*

Confusion regarding drug regimes and purpose and side effects of medication featured in several interviews, Box 4.14. Wives usually took some, if not most of the responsibility for monitoring, obtaining and often administering medication. A potentially life-threatening psychosis thought to be due to steroid medication was recalled by one patient, Mr I, Box 4.14. Steroids had been prescribed for loss of energy and appetite, the patient then went on holiday abroad, became confused and suffered a dramatic episode in which he broke into a foreign hospice. He recalled wanting to be admitted to a hospice but when he got there, early in the morning, it was closed; he climbed over the wall and fell into the courtyard. Fortunately the staff realised he was confused: he was transferred to a psychiatric hospital and sedated until fit to travel home. Intriguingly, this patient partly blamed himself for this episode. The cost to the patient, and to his wife who had to deal with this episode away from home, was considerable in terms of distress and potential harm. Another patient gave a clear description of having had potentially serious gastric side effects of steroids.

### **Box 4.14: Medication issues**

*Mr M: 'I was getting a bit of pain in my chest but they changed me off these co-proxamols, taking 6 of them... So they put me on prednisolone, take 4 of these in a morning you know and give me enough for a fortnights trial... so I knocked the co-proxamol off like and that's when I was getting a little bit of pain on the ribs here like...the Macmillan nurse come to see me like she more or less played hell with me. Well I didn't know like I had to take them as well.'*

*Mr J: 'I'll eat, the appetite's good at the moment 'cos I'm on steroid tablets ...and that's the only treatment I'm on. The indigestion, it's terrible and weight, it's not brilliant but it's a lot better than what it was... I do take a sleeping tablet with me vodka because it works.'*

*HC: 'You can deal with it even if it is a nasty pain?'*

*Mr U: 'Well I can deal with it enough yes. Now, like yesterday was a bad day and it's a lot of the medication. And the lollipops [transmucosal fentanyl]...if one doesn't work take two and one didn't work and I took two and it went like that.'*

*Mr I: 'It was in the second week of our holidays, I was not right...I started to smoke a lot more, a hell of a lot more, started to drink a lot more....mood swings..., I was at that stage of life, being diagnosed the way I was, why should I worry if I upset someone through a slip of the tongue.... Well I thought I was Jesus, that was the crunch. I thought I could cure anything and do anything...I started to drive the wife up the wall...wasn't sleeping, an hour was enough...I was walking around, no money in my pocket and buying drinks at a bar and walking out.'*

*HC 'Did you have any insight, did you realise things were going wrong mentally?'*

*Mr I: 'Oh yeah, I thought it's got to be the tablets, a combination of tablets and drink...I was still behaving like God.. I said 'I really need help, the way I feel you could take me to the cop shop and bang me up, just out of harms way 'til I sort myself out.'*

## 4.8 State benefit claims, civil compensation and coroner's investigation

### *State benefits*

All the patients interviewed were unimpressed with the systems for State benefit claims including Industrial Injuries Disablement Benefit (IIDB). Delays, misunderstandings, insensitivity, the need to establish causation and the work ethic culture in which the interviewees had been raised caused stresses for the patients and their families, most of whom had not claimed benefits previously. The lack of entitlement to IIDB for those without a history of *occupational* exposure to asbestos caused additional distress. The need to undergo a medical examination in order to confirm the diagnosis offended one patient and caused a great deal of anxiety as he felt he may need to convince the doctor of his entitlement. Others were inconvenienced and upset when they had to travel to a benefits centre for the examination.<sup>30</sup>

Many expressed appreciation for help in accessing benefits, in particular from the Macmillan or specialist lung nurses who had assisted in completing complicated claim forms – some patients admitted that they would not have pursued a claim without this help. Although it is not a part of the role of a Macmillan or specialist lung nurse, they appeared to fill an important gap in services for these patients as social workers or benefits advisors did not feature in any of the interviews, Box 4.15.

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<sup>30</sup> The requirement for a medical examination has since been removed from the regulations.

#### **Box 4.15: Claiming State benefits**

*Mr Q: 'they sent me a pile of forms that big back to fill in....but every word, every sentence was about where I'd worked. I filled them in, I wrote back and said "It's nothing to do with where I worked, it's where I lived". So they said "Oh, we'll send you some more". But again ...mostly where I worked and a few about where I lived. So I filled them in but I can't see that doing much.'*

*Mr M: '(the lung specialist nurse) was here, on with the Social, about telling them they'd put the wrong thing on my claim. She'd told them about what I'd got..but the woman at the Social said that she's having difficulties in getting people ' cos British Rail has now broken up... she's just getting passed from one to another to another to another ....nobody wants to know now.'*(patient Mr M)

*Mr D: 'She (the lung specialist nurse) filled the forms in, if it wasn't for her I wouldn't have been able to claim anything...My view on claiming is I don't see why the people in the Social or NHS should try and do you out of your money.....I've got a Disablement badge for the car, I didn't even know I could get that, she filled the forms in on Friday and I got it Saturday... that was very quick.'*

*Mr J: 'She (the lung specialist nurse) filled the forms in – cracking lass that, and we haven't received anything yet...I'm still waiting for some crazy doctor to come to disprove what the hospital proved, and that's my worry. She said, and the other doctors have all said "When he comes tell him the worst". Well if he'd come at the beginning, well there was nothing of me...the weight's back on again now...I'm not doing any exercise and I'm not working but it gets to me. I've always wittered, but I am bothered. And how can I sit there and say...well I'll get cold feet like. I'll have to do summat (meaning he'd have to demonstrate his breathlessness on exertion to the examining doctor) that'll be the only way. And it's taken too long as well, and I get up every morning and ...has it arrived? (the appointment with the examining doctor). I want to get it all over with and let me get back to what I want to do. I won't be running but at least we can get out.'*

#### *Civil compensation*

Most patients were also involved in claims against former employers for civil compensation on the basis of negligence regarding exposure of the workforce to asbestos. One patient could not understand why her solicitor appeared uninterested in her belief that she had been exposed to asbestos in the market where she had worked but concentrated instead on her history of washing her son's and husband's overalls from the shipyard; she failed to realise that the legal case for establishing causation and thus a successful claim for compensation was much stronger against the shipyard than a test case against the market. It appeared that the requirement to provide details of past employers, and in some cases having to contact former workmates to give statements, was extremely demanding and often the task fell mainly to the patient's spouse. One patient recalled media reports of the situation in other countries. Although mentioned with humour, Mr V, hinted at the anxiety about attending court in order to pursue his compensation claim (see Box 4.16).

#### **Box 4.16: Civil compensation claims**

*Mrs N: 'They keep asking me where I've worked...I've been a canteen assistant...well you're not exposed to it in a canteen are you?...he keeps asking about the overalls...I thought that would be of benefit to him, the first case off a market when it is full of it. '(patient Mrs N)*

*Mr U: 'There was something on Teletext about other countries claiming now, I think it's a British firm and there's a load of people.. I'm trying to think where this South African thing...whether it was before or after the war...There's something in the back of my mind that I saw lads mining it (asbestos)... A long long time ago.. and then you start to think now, how did they know then?*

*Mr V: 'I don't know why it should be a trial – I haven't done anything wrong!'*

### *Coroner's investigation*

The procedures after death, formal identification of the body and post mortem examination, were referred to by two patients. One knew from his father's death due to mesothelioma, the other had learnt from newspaper reports. None mentioned the inquest – possibly because this was just too distressing to discuss in front of their spouses, Box 4.17.

#### **Box 4.17: The Coroner's investigation**

*Mr J: 'I know how bad me Dad was, the police came and we had to go there, we'd been there Christmas Day. So that always sticks in me mind.'*

## **4.9 Health service provision**

### *Appreciation*

The patients were mainly very appreciative of their local health services but had some ideas about improving efficiency and communication, particularly when modern technology was involved. Good relationships with GPs, consultants, and the lung specialist nurses in particular, were valued. Being made to feel a 'special' patient by professionals who were seen to be particularly helpful was much appreciated: for example, the surgeon who immediately proceeded to biopsy a suspicious chest wall mass and nurses who called regularly and reliably; in these circumstances warm and trusting relationships developed.



### *Lack of local facilities and postcode medicine*

Problems due to distant locations of tertiary centres mainly affected the patients from Barrow. Radiotherapy for Barrow patients is provided in Preston, 70 miles away and the nearest Thoracic Surgery Unit is in Blackpool, 80 miles away. This caused problems for some patients: one woman initially refused to be admitted to a distant hospital for pleurodesis and the discharge of another patient was delayed due to lack of transport over a Bank Holiday. However, two of the patients tried to make the best of the situation and proudly described how they had organised accommodation in Blackpool, likening it to a 'mini-break'.

Physical access to treatments was also affected by simpler matters such as the difficulty in parking close to any of the hospitals relevant to this study, the physical effort that breathless people have to make to get from the car park to clinics, and the exhaustion caused by lengthy ambulance trips that transport several patients on the same journey. These issues compounded the burden of investigations and treatments.

For some of the interviewees, particularly those with repeated effusions and both post-surgical patients, hospital doctors had made special arrangements for them to bypass the Medical Assessment Unit. Others had been given contact numbers for lung specialist nurses or, in one case, the consultant's secretary's office, but these were only manned 9am to 5pm weekdays. In the age of mobile phones it is easy to assume everyone can use a telephone but one elderly man had problems because he had never had a phone before his illness. He was distrusting of answer-phones and felt abandoned by the lack of personal contact.

#### **Box 4.18: Care in distant hospitals**

*Mr D: '...it took them 8 weeks to sort me out and I think that was very good...'*

Later in the interview, referring to Blackpool cardio-thoracic unit

*'...you could go in anytime you wanted... except between 1 and 2pm I think, they had to have a rest, a sleep.'*

*Mrs D: 'Yes it were really quite relaxed and yet they had open heart surgery on the same ward ...I thought flipping heck...everything's so relaxed and easy.'*

*Mrs N: 'I said, 'Oh no, I don't want to go to Blackpool...The only reason I didn't want to go, 'cos I like my home and he'd have to be running up and down that motorway.'*

*Mr M: 'I was in there 10 days, being a Bank Holiday I had to stop in 2 extra days, er, I could've come out but they couldn't find any body to fetch me!'*

*Mr D: 'The wife stayed there with us. I got her in a bed and breakfast, there was one, it was only 5 minutes walk and the wife said it was great'*

*Mr I: 'Absolutely perfect because we had too many holidays you know down at Blackpool and we thoroughly enjoyed it....Well we used our business sense – Why travel backwards and forwards to Barrow in the car using petrol up, tiring, mileage...She had all day to herself to go around – pre-Christmas shopping. We stayed with friends that we'd known for years'*

### *Inefficiencies*

These patients were usually under the care of several hospital departments, the specialist lung nurse and possibly a Macmillan nurse as well as their GP. Two of them, the two with most advanced illness were also under the care of the palliative care team. Some patients were bewildered by the number of doctors involved and could not determine who was meant to be in overall charge. Poor appointment management and communication breakdowns caused a lot of anxiety. Patients' wives often had to chase up appointments. One patient, Mr T, had five appointments in one week at a variety of hospitals, his wife took advice from the Macmillan nurse in deciding which to cancel and she also commented that parking is a major problem for patients who are breathless and frail. During the hour that I spent with the most seriously ill patient, who died six days after the interview, there were four interruptions: the district nurse and the Macmillan nurse visited separately, the hospital appointments clerk rang, and a friend rang too (Vignette 4.2, Mr C).

## Patients' comments

At the end of each interview patients were asked if they had any suggestions for improving care of people with mesothelioma. Only this one patient responded: Mr I suggested that anyone with a history of asbestos exposure should immediately request a chest x-ray in the hope of detecting mesothelioma at a curable stage. Sadly there is no evidence for this being effective at this time.

### Box 4.19: Inefficiencies in care

*Mr M: 'When I come out (the consultant) he said 'I'll see you in a month's time', well it got to be a month then he put it back another 4 days and I don't know but that nobody's interested in me and I tried one, one or two times to get through to [specialist lung nurse] and I couldn't and I tried to get through there to [Macmillan nurse] one time and I couldn't get through to her... What's the point in having a direct phone if you can't get through to them?... Yeah, she says you can page me like... and those answering machines, I don't like them at all, I'm not used to phones but I think knowing what I know now I would have had a phone a good while ago.'*

*Mr J: '...he checks me out with his stethoscope and says 'I want you to go and have it drained and an x-ray' but we heard it was a 2-hour wait...so go and get your blood sample first....done immediately...went back and [waited] an hour. Now...if I was running this business...you know what the course or plan is going to be, right? Your appointment, your x-ray is such and such a time, get your blood done and then one hour or half hour later you're in! If it was business it would be done that way.'*

*Mr H: '...they told us to go "Ring if there's a bed" and there was and we went. At 3.30 the nurse came and says "Sorry but the consultant isn't in the hospital this week.'*

*Mrs G: 'No, you didn't hear any more for ages. The nurse had told you she hadn't drained it all but Dr B would give you some tablets to drain the remainder. But it just went on and on and I said, 'When you come home from golf, call at [the hospital] and see what's happening.'*

*HC: 'So what happened then?' Mr H: 'There was an appointment for me, wasn't there?'*

*Mrs H: 'Mr V wanted to see you immediately, and it was the best day's work we ever did, that, wasn't it?'*

#### **Vignette 4.2: Mr C – “Devastated”**

*I knew from his Macmillan nurse that Mr C was deteriorating rapidly but Mrs C was adamant on the phone that they both wanted the interview to proceed saying ‘What we’ve agreed to do we always do.’ Their home was a neat terrace house near the site of a previous asbestos textile factory – demolished over 40 years ago. Mr C had been exposed to asbestos as a plumber.*

*In the sitting room Mr C was sitting hunched over in a wheelchair – he looked extremely ill. He had piped oxygen via nasal cannulae but in spite of that his face was grey, his hands purple and his feet, protruding from pyjamas, were grossly swollen and bulging over the tops of his slippers. It was an effort for him to raise his head. I went over to introduce myself and shake his hand – it felt cold in spite of the room being extremely warm. He nodded his head then whispered ‘Talk to the wife’. He looked much older than 66 years.*

*Mrs C started to give details of her husband’s illness that had begun just a few months before he was due to retire. She was very upset and unable to concentrate due to interruptions and her own distress. Once she got to the part where they learnt of the diagnosis I asked ‘How did you react to that?’ and Mr C just raised his head and said ‘Devastated.’ At this point Mrs C started crying and I tried to console her. Mrs C wanted to carry on with her story but was interrupted by a phone call from a relative. Then Mr C wanted to go to bed and she helped him in his chair to the stair lift and eventually up to his bed. My offer to help was refused ‘We’ll manage, we’re alright.’ She came downstairs after about 10 minutes then the district nurse came in to check Mr C’s syringe driver. After she left a hospital secretary was on the phone about appointments which Mrs C then cancelled. Mrs C was insistent that I heard the rest of the story, the main issue was the loss of all their plans for retirement but interspersed with this were stories about their recent burglary (in which their dog was stabbed) and their children. Mr C called for her twice more and she went up to attend to him.*

*The nurse returned with medication from the chemist and after she left Mr C called for his wife again, he then went to sleep. Eventually Mrs C settled down and thanked me for coming and for listening to her – she hoped it might help to improve things for others. Mrs C said that her daughter was calling after work. I thanked her for giving her time in such distressing circumstances and assured Mrs C that her information had been very valuable.*

#### **Summary**

In this section I outline the key findings from this chapter. These findings will be brought together with the other data sources, and with reference to the literature, in the Discussion, Chapter 7.

As in previous reports, the majority of patients interviewed had been exposed to asbestos in industrial settings, two patients recalled para-occupational or environmental exposure. Multiple routes of exposure were common, affecting 6

of 15 patients. Most of those exposed to asbestos at work could not recall any asbestos hazards advice. Warnings of asbestos hazards that were recalled by two patients were ignored at the time: one man apparently did not appreciate the seriousness of the risk, the other recalled warning concerning blue asbestos but believed they did not apply to him as he was working with white asbestos. One man took the warnings seriously and moved to a 'cleaner' job. Anticipatory anxiety usually developed as patients learnt of workmates succumbing to asbestos-related disease or from media reports. Pre-diagnosis, patients feared developing the disease; post-diagnosis, patients feared suffering from severe symptoms that they had heard about indirectly. Anxiety post-diagnosis extended to family members, some of whom worked in the traditional industries that had used asbestos in the past. All the patients knew that asbestos had caused their illness but the lack of hazards warning and the long latency caused some disbelief. Attribution was complex due to the consequences of accepting the former employers as negligent and, in some cases, elements of self-blame.

Initial symptoms were attributed to common minor conditions or aging. Presenting symptoms agreed with previous accounts and were related by patients with regard to their impact on daily life. Increasing knowledge around symptoms could empower or, alternatively, worry patients. Married couples reported dealing with symptoms together and although patients were generally reluctant, their wives often took the lead in calling for help. Breathlessness caused severe anxiety for patients and their families, it brought fear of impending death or signalled disease progression. None of the patients was aware of self-help techniques for breathlessness. Some patients had experienced severe pain but the patients mostly denied severe pain at interview. However it was evident that some expected pain as a consequence of cancer. The unpredictable disease trajectory, uncertainty around disease progression and prognosis, and failing health, caused distress.

Most patients experienced multiple investigations and interventions. The perceived burden of these procedures varied considerably but was distressing for the majority of patients. Complications were reported for some invasive procedures. Patients recognised that in some cases junior doctors performing the procedures were being trained in the techniques. Prophylactic radiotherapy to prevent tumour tracking was ineffective in one case. One of the two post-

surgical patients had evidence of disease progression. Complexities and misunderstandings around treatment decisions caused distress

Senior doctors had disclosed the diagnosis. The terminal nature of the disease, short survival and lack of curative treatments had been explained in every case. The entitlement to specific State benefits and civil compensation had usually been explained in the same consultation as the disclosure of diagnosis. In most cases the patient's spouse had been present when the diagnosis was disclosed but in two cases the patients' wives had been told first and this caused additional distress.

Shock and/or stoical acceptance were the most common reactions to the diagnosis. Patients (and their relatives) clearly recalled the *manner* in which the doctor broke the bad news. After the shock of the diagnosis most patients displayed an unquestioning acceptance of the diagnosis. Patients relied mainly on their families, particularly their spouse, for support. Patients and their families appeared to have negotiated how to cope with the illness together. Some patients, knowing they had a terminal illness, focussed on measures to stay healthy. Patients (and their spouses) emphasised that they were coping with the situation even when it appeared that their situation was particularly difficult. Male patients in particular, appeared to minimise emotional distress and were less prepared to discuss emotional issues than the women. The two female patients took practical measures to prepare for death in contrast to the male interviewees. Loss of normal gendered roles and functions, including active hobbies and sexual function, as well as altered body image due to loss of weight, caused great distress.

Most spouses attended the interviews with patients and contributed to them. In the interviews, the spouses sometimes used strategies to reduce emotional tension. The supportive role of the spouse was seen as including minimising distress, help-seeking and information gathering, as well as physical and domestic care. Couples' relationships often intensified, some became more strained.

Several patients reported confusion regarding medication and medication side-effects were common. Serious, potentially life-threatening, well-known, side

effects of steroids were reported by two patients as well as common side effects of analgesics.

None of the interviewees was familiar with the State benefits system and most found the procedures complex and distressing. Most patients needed help, (usually from Macmillan nurses), with form-filling. The (no longer necessary) requirement for an independent medical examination caused offence, distress and inconvenience. Most patients were pursuing civil compensation claims but the legal procedures were unfamiliar and provoked anxiety. Two patients referred to the inquest but none referred to the post mortem examination

Patients and their families were mainly appreciative of the services they had received, in particular, good relationships with healthcare professionals and special arrangements that made treatment or management more efficient and less distressing. Patients found that they had a bewildering number of doctors, hospital departments and often several hospitals involved. Criticisms were directed at inefficiencies with appointments, distance to tertiary centres, poor communication and information, as well as practical difficulties for breathless patients such as difficulty parking, long distances to walk in hospitals, and long ambulance journeys.

# Chapter 5: Focus Groups with bereaved relatives

## 5.1 Introduction

As discussed in the Methods chapter, six focus groups were conducted with bereaved relatives, two groups in each of the three locations. Only one related caregiver/patient couple took part in the study: Mr I, a patient, interviewed a week before he died, and his wife, Dora, who participated in Focus Group 1 four months after his<sup>31</sup> death. The other interviewed patients and focus group participants were not related<sup>32</sup>. In some cases the bereaved relatives were discussing care that they had witnessed or experienced from healthcare professionals interviewed in Chapter 6. As discussed in the Methods chapter, care has been taken to preserve anonymity and confidentiality with respect to patients, relatives and healthcare professionals who participated in the study.

Quotes relating to the subheadings are placed in boxes at the end of each section, in some cases the actual quotes are inserted in the text if this helps to illustrate a specific point. As described in the Methods chapter, each quote is numbered with the chapter and box number followed by the individual quote number, thus in this 5<sup>th</sup> chapter, the fourth quote in box 5.5 becomes 5.5.4. Names of the participants have been changed and each name is followed by the focus group (fg) number, for example, Amanda, fg1. Parts 1 to 3 refer to the relatives' experiences as carers, part 4 describes their experiences of the socio-medico-legal issues. As also described in the Methods chapter, the terms relatives, participants and carers are used interchangeably to avoid frequent repetition. Similarly the recipients of care are usually referred to as patients and occasionally as loved ones.<sup>33</sup>

The focus groups were highly emotional; this was in stark contrast to the controlled and stoical reports from the patients who had been interviewed<sup>34</sup>. Bereaved relatives described the 'roller coaster' experience of living with someone suffering from mesothelioma and the physical and emotional impact

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<sup>31</sup> Dora refers to her husband as Bob in the groups.

<sup>32</sup> This limitation is described in the Methods chapter.

<sup>33</sup> It appeared that all the care recipients referred to in the focus groups were 'loved ones.'

<sup>34</sup> See Methods and patient interviews, chapters 2 and 4



that it had on them as the main carers. Their accounts were not neutral: participants were self-selected volunteers, all were still grieving and many were angry about the illness or aspects of the care provided. Some accounts caused tears and on occasions participants comforted one another, at other times a break for refreshments, handing out tissues, or laughter, dissolved tensions. Anger was expressed towards the authorities that relatives felt had let them down: governments; employers; health and safety advisors; the healthcare system; lawyers or individual professionals. Their narratives may have been somewhat rehearsed in being told to family and friends and recalled through the lens of loss<sup>35</sup>. My role as researcher, and as a GP and hospice doctor working near Barrow-in-Furness and with a particular interest in mesothelioma, may also have influenced their stories<sup>36</sup>.

## 5.2. Awareness, learning the diagnosis, and information

### *Awareness: Living with worry*

*'I had him dead and buried then, because I'd nursed people with mesothelioma.'*  
(Susan, fg2)

The focus group participants reported anxiety concerning the risks of asbestos-related disease prior to the diagnosis of mesothelioma, echoing the patients' interview accounts<sup>37</sup>. This anticipatory anxiety, described by de Villiers (1997) as the 'Damocles syndrome', related to pre-existing pleural plaques in some cases, previous deaths due to mesothelioma in workmates or occasionally other family members, and/or media reports of asbestos-related diseases. However, even when they had been aware of asbestos health hazards, relatives had not always acknowledged that these risks applied to their own families, 5.1.1. Four relatives recalled that their loved ones had emphasised the likelihood of the diagnosis being asbestos-related, in three cases telling the relatives to insist on a post mortem examination if any doubt remained after their deaths, 5.1.2, 5.1.3. Once the question of asbestos-related disease had been raised by doctors, relatives reported an increasing sense of dread as they realised the

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<sup>35</sup> One participant, Lynn, subsequently sent me a copy of her comprehensive written diary of her husband's illness, death and the medico-legal procedures before and after his death; in many areas the written text mirrored her spoken contribution to the focus group. This is considered in the Methods chapter.

<sup>36</sup> All participants in the study were aware that I was a GP and hospice doctor as well as the researcher.

<sup>37</sup> In Chapter 4

possible implications. As knowledge about mesothelioma increased, some participants reported then becoming aware of risks relating to other family members; for one participant the group discussion revealed her own risk for the first time from exposure to asbestos on her father's overalls<sup>38</sup>, 5.1.4.

As awareness fluctuated during the illness the relatives reported how they had to keep within the boundaries set by the patients, varying their approach and often using careful negotiating techniques if they tried to address issues related to the future, dying or death. Participants described how tact and sensitivity were needed in dealing with the emotional minefield of patients' feelings, autonomy and independence. However, two groups laughed together as participants described how humour was used at times to lessen the emotional burden, similar to the interviews with patients, 5.1.5, 5.1.6.

Relatives described specific anticipatory anxiety concerning the mode of death. It appeared that this was based on remarks made by health professionals, the media and, in some cases, by patients. They recalled frightening descriptions they had either heard or witnessed:

- *'it's like a net that goes around the lung and chokes them'*,
- *drowning in his fluid'*,
- *'agonising death'*,
- *'the worst sort of death'*.

Three participants in Focus Group 3 and one in Group 6 told that they had been able to discuss funeral plans with their relatives well in advance. Two participants avoided the issue until it was obvious that death was imminent, others found it too difficult to address. Some recalled that raising the subject of funerals might be seen as evidence of 'giving up'.

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<sup>38</sup> The potential harm resulting from this discussion had not been anticipated. This issue is discussed in the Methods chapter, p85 with an account of how it was handled.

### **Box 5.1: Awareness**

1. *'...we didn't equate the fact that he'd worked amongst it all those years ago with it being dangerous for him'* (Janet, fg5).
2. *'...and he'd have his tea ,I'd fight with him on the floor and he's got his overalls on. Has it happened to me? My brother?'* (Alan talking about his father, fg1)  
*'You're making me think now, I never even thought of that...'*<sup>1</sup> (Amanda, fg1)
3. *"Always remember if ever I take ill later on in life, I worked with asbestos, don't let it go.'* (Pam, fg2)
4. *'She had it put in her will, that she wanted a post mortem, because she knew it was mesothelioma and not a secondary from breast cancer'* (Joy, fg6, whose mother had made asbestos mattresses in her 20s)
5. *'His 2 sisters came to see him... his older sister said "Hasn't our Joss got lovely skin?" and my husband turned round and said "Bloody hell Betty, I'm dying, and all you can say is that!'* (Pam, fg2)
6. *'She told me not to wear black 'cos it didn't suit me!'* (Joy, fg6)
7. *'...I couldn't do it because, well I did, sort of 3 days before he died I had to ask him and he just left it up to me'. (Grace, fg3, recalling difficulties discussing funeral plans)*

### **Learning the diagnosis**

*"You're telling me it's terminal?"' (Edna, crying, fg4)*

Relatives reported that reaching the diagnosis could be a difficult, lengthy process that caused intense anxiety. In many cases less serious meanings were ascribed to initial symptoms, mirroring the alternative attributions described in the interviews with patients. Ten of the 17 participants recalled that they had never heard of mesothelioma before. Relatives reported finding uncertainty particularly difficult to deal with: suspected, but not histologically confirmed, mesothelioma resulted in confusion around prognosis and left families in limbo regarding benefits and claims procedures.

One wife recalled prompting her husband's doctors to consider asbestos-related disease; although he had been aware of his risk he had not mentioned it to his doctors, but was not surprised when mesothelioma was diagnosed. In another instance the patient's stepson, a doctor, suggested the diagnosis but was given false reassurance initially. Regardless of any prior knowledge or suspicion of mesothelioma all but one of the relatives recalled reacting to hearing the diagnosis with shock. Participants described this reaction as an extremely

physical response as well as an emotional shock, 5.2.1, in marked contrast to the reported stoicism which characterised the patients' reactions<sup>39</sup>. The exception was Don, (fg 2), who told how his father had convinced the family that he knew he had mesothelioma before the doctors were sure and the visible rapid deterioration in his health also confirmed to the family that he was terminally ill. After the death of Don's father, the family found an article from the Readers Digest in his wallet: written in the 1970s, it described the health hazards of asbestos exposure.<sup>40</sup>

Relatives confirmed patients' accounts regarding disclosure of the diagnosis: doctors explained the terminal nature of the disease, lack of effective treatments and, usually at that time, encouraged them to make claims for state benefits and civil compensation. In just one case the diagnosis was withheld from a patient: this was at the daughter's insistence based on her understanding of her elderly mother's personality. This daughter found it helpful to pretend that there was nothing seriously wrong with her mother initially, 5.2.2. She told how she had predicted that her mother would just 'give up' when she learnt she had a terminal illness and sadly that proved to be the case. Several relatives reported dissatisfaction with the way in which the bad news had been imparted; these accounts created much distress amongst other group members<sup>41</sup>. Their criticisms related to lack of privacy; perceived insensitive or callous remarks; undue emphasis on the benefits and compensation claims; telling the patient without a relative present and telling the spouse before the patient, 5.2.3, 5.2.4, and Box 5.3. One relative, a nurse, recalled how confidentiality was cited as the reason for not informing her of her father's diagnosis in spite of him leaving explicit instructions for her to be informed.

Two relatives in Focus Group 3 were shocked to discover that a consultant had used the same upsetting phrase to both of them when asked about prognosis:

*'How long is a piece of string?'*

This may have been a trite reply that the doctor had developed in order to deal with an emotionally-challenging and difficult question, but these two relatives, and the other group members on hearing these reports, had been outraged.

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39 As described in the interviews with patients, Chapter 4

40 This may illustrate an example of anticipatory anxiety prompted by a media article many years before the disease developed and kept safe 'just in case'.

41 The groups managed this distress without intervention from me: although upsetting accounts echoed the experiences of some other participants there was a sense of group support for the distressed relatives and an agreement that these types of communication had been unacceptable and unfeeling. This appeared to comfort the reporting relatives.

The hopelessness of the message could be hard to bear, particularly when participants felt abandoned or frightened by healthcare professionals. One participant was still angry at the message she perceived:

*"You've got a terminal illness, go away..."* (Grace, fg3).

As with other reports, Grace may be recalling her interpretation of the conversation rather than the literal truth. However this quote does reflect the perceived effect of the communication from the doctor, which was presumably not the intended result. Similarly Susan (fg2) paraphrased what the radiotherapist *'more or less'* said to her husband:

*"There's nothing I can do...I can only offer you radiotherapy if the pain gets too severe".*

Although surely unintended, the last remark may have been interpreted by the anxious patient and family as predicting inevitable severe pain.

It is difficult to assess how much the shock of the diagnosis may have affected recall – several relatives described being 'numb' when they heard the diagnosis, mirroring the patients' reactions<sup>42</sup>. Similarly these accounts must be seen in the context of bereavement and, as mentioned earlier, as retrospective and rehearsed narratives with implications for the moral reputations of the relatives.<sup>43</sup> At diagnosis some relatives reported suddenly feeling isolated as a future without their spouse became clear. Lack of support or someone to talk to at the time of diagnosis was mentioned by some, others were annoyed by well-meaning solicitous remarks from nurses. Many relatives recalled just wanting to get away from the hospital and take their loved ones home. Once mesothelioma was diagnosed relatives recalled how they (and the patients) had little opportunity to avoid physical, social and medico-legal reminders of the illness.

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<sup>42</sup> Reported in Chapter 4.

<sup>43</sup> These issues are discussed in the Methods chapter.

### Box 5.2: Learning the diagnosis

1. *'... it just felt as if someone had gone "Arrgh" like that, punched you in the stomach. It actually winded me'* (Gillian, fg4)  
*'It was just the same.'* (Edna, fg4)  
*'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)  
*'You feel like hitting them don't you?'* (Edna, fg4, all the group laughing)
2. *'When you hear people say the word cancer you think of death straight away. I didn't try to block it out of my mind but I tried to carry on with everyday things, and to treat my mum as if she was just in hospital with a cold, that's how I tried to cope.'* (Janet, fg 3)
3. *'Now trainees, I understand it's a teaching hospital, but it's not a teaching hospital for bereavement or for anybody to see agony or anything.'* (Dora, fg1)
4. *'Dreadful, I feel angry. Yes, completeness anger, and I'd like to go and tell them off, but (laughing)...I don't know whether it's the thing to do or not.'* (Jean describing her feelings about her husband being told when she was not with him, fg5)
5. *'..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)

### Box 5.3: Breaking bad news badly

Dora went to see the consultant with a friend of the family while her husband was an inpatient:

*'...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 says "Pardon?"'*

She recalled that the consultant repeated his advice to make a will and told her that Bob had only got 2 weeks to live:

*'That's how he said it, in front of everybody. He says "Now we'll go to the ward and see Bob"'*

They went to the ward where her husband was with 5 other patients who were having investigations:

*'...he put a curtain round and he brought 3 trainees with him'.*

After the consultant had told Bob the same as he had told Dora she recalled he asked:

*'"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)

This account may not be the precise literal truth but may reflect Dora's perception of the content of the encounter which undoubtedly included distressing and inaccurate information. (Her husband Bob ( Mr I) actually lived for 15 months.)

(See Boxes 4.9 and 4.14)

### Information

Heated discussions about healthcare professionals centred around poor or inadequate communication and information. The relatives agreed that they expected a senior doctor to take prime responsibility for informing the patient *and family* about the diagnosis and explaining treatment options. Conflicting,

unclear or inaccurate information from different doctors or different advice given to relatives and patients were reported as causing distress and loss of trust. Relatives reported being frustrated by the apparent unwillingness of some healthcare staff, particularly doctors, to share information with them about the illness. Some had approached other healthcare professionals, particularly if they had family members in healthcare, or their GP, for more information. Several relatives had found distressing and sometimes confusing information via the Internet; at times relatives would censor information available to the patient in order to protect them from additional distress<sup>44</sup>, some relatives wanted to know more than the patients. With hindsight bereaved relatives acknowledged the difficulties in advising about treatments of negligible value and burdensome clinical trials but this had not necessarily been understood at the time. Their experiences had led many relatives to conclude that not all the professionals were knowledgeable about mesothelioma which caused disillusion and loss of confidence. (See Box 5.4).

Even when patients were obviously dying it appeared to some relatives that there was sometimes lack of honesty from doctors. One participant described how she suspected that the doctor was *'telling porkies<sup>45</sup> again'* when he said her husband's prognosis *'...could be 1 year, could be 3, could even be 10.'* (Jean, fg5) One wife recalled that the reluctance of hospice staff to admit that discharge home was unlikely for one dying man meant that she wasted precious time trying to get their house organised when, with hindsight, she wished she had spent the time by his side.

Relatives reported general appreciation for Macmillan nurses and for their role in explaining the illness and treatments, although their involvement was delayed in some cases by the association of the Macmillan name with dying:  
*'...you think 'Macmillan nurse'... the Grim Reaper's<sup>46</sup> coming in'*

For some relatives, and patients too, this association was uncomfortable and thus limited their access to information. Some relatives described feeling responsible for accessing and managing information, others described how the

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<sup>44</sup> Conversely, some patients filtered information in order to protect their relatives at times as reported in Chapter 4.

<sup>45</sup> 'Porkies' refers to Cockney rhyming slang for lies: pork pies = lies.

<sup>46</sup> The Grim Reaper is a common representation of death.

task of finding out all they could about the illness gave them a sense of purpose. In one case the relative reported that the family believed that the Macmillan nurse did not know anything about mesothelioma and they decided her visiting was pointless, unfortunately they lived outside the area covered by the specialist lung cancer nurse.

#### **Box 5.4: Information**

1. *'Bob wouldn't look at it, I'd got books because I wanted to read, and he got very annoyed at me, and he said "If I see one more book about cancer come into this room..." (Diane, fg1)*
2. *'...I was never told anything about what it was going to be like...I kept asking "What have we to face? What symptoms have I to look for?" and I was just told "Oh, it'll come".'* (Edna, fg4)
3. *'I was becoming sort of fired up, wanting to find out as much as I could and I think that kept me going. I was on a crusade then to try and find something to keep him alive.'* (Grace, fg3)

### **5.3. Experiences of the healthcare system**

#### *Investigations and treatment*

*'Well the first time he went in, obviously his lung was practically [full] to capacity, and it is our opinion that the man who did it was learning.'* (Jean, fg5)

Relatives described the tension between their sense of responsibility for the care of their loved one and their feelings of helplessness in the medical setting. Relatives expressed distress concerning the multiplicity of investigations conducted, the traumatic invasive nature of many procedures, and the frequent delays in obtaining results – continuing anger was evident in all the groups, 5.5.1. They described the traumatic experience of witnessing medical emergencies as most of their loved ones suffered repeated emergency admissions for breathlessness due to recurrent pleural effusions<sup>47</sup>. Relatives reported with horror and incredulity the large volumes of pleural fluid, up to 4 litres, aspirated, 5.5.2. Three relatives voiced concerns that some invasive procedures were apparently performed by inexperienced doctors<sup>48</sup>. One of these relatives recalled requesting that the respiratory consultant would perform subsequent aspirations and his response:

*'...other doctors usually do this'.* (Diane, fg1)

<sup>47</sup> See medical records review, Chapter 3

<sup>48</sup> As similarly described in the interviews with patients, Chapter 4.



Another wife told how her husband had been in severe pain during a pleural aspiration such that another patient on the ward had remarked:

*'I don't know how you put up with that'* (Jean, fg5)

Relatives reported anxieties about side-effects of medication, particularly drowsiness and confusion, 5.5.3. One relative recalled her husband suffered a life-threatening psychotic reaction due to steroid prescribed to stimulate his appetite<sup>49</sup>, treatment commenced just as the couple went abroad on holiday. According to the wife (Diane, fg1), and corroborated by her husband's account (Bob, Mr I, p156)<sup>50</sup>, he suffered a dramatic personality change that resulted in emergency admission abroad, causing much distress and inconvenience, 5.5.4. In one case a wife, Sue, fg6, described how her husband had a paradoxical response to sedatives on three occasions: he became extremely agitated and confused, unfortunately including some hours leading up to his death.

Two wives reported that their husbands had become debilitated while having chemotherapy and they reported difficulty in knowing whether that deterioration was due to effects of treatment or disease progression. Relatives reported anxiety about chemotherapy in the light of medical uncertainty: one wife reported the consultant's words:

*"...it might stop it advancing as quick, we don't know, but there is that possibility."*

Participants described the delicate and difficult process of supporting their relatives when they tried to decide whether or not to accept chemotherapy, 5.5.5. Although the participants described how the decision was usually made jointly, some of the wives had not voiced their own views if they had differed from their husbands': they did not want to add to distress by appearing not to support their husbands' decisions. With hindsight one wife reported her belief that her husband might have lived for an extra month without treatment.

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<sup>49</sup> Steroid treatment is only recommended for short-term stimulation of appetite; safer alternatives are available. Acute psychosis is a recognised side-effect of steroid treatment, this patient was possibly at higher risk than normal as he had a past history of significant psychiatric illness.

<sup>50</sup> Diane and Bob (Mr I) were the only patient/carer dyad who participated in the study as interviewed patient and subsequently bereaved wife respectively.

### Box 5.5: Investigations and treatments

1. *'...and it's waiting for the results that's worse than the actual results themselves.'* (Gillian, fg4)
2. *'...over a matter of a few days they drained 5 ½ pints of fluid off his lung...They said if he'd been left any longer he'd be drowned (Edna, fg4)*
3. *'...he was totally away with the fairies, in fact I don't think they knew what was wrong with him. He had to have a catheter and he was vomiting dreadfully, nasty stuff coming up, but afterwards he said he had no recollection of any of it' (Jean, fg5).*
4. *'... he was admitted... to a mental institution through the drugs he was on, sent him doolally(crazy), he tried to kill me...and then they wouldn't let me see him for 3 days...by the time I saw him he was a broken man.'* (Dora, describing a steroid-induced psychosis that occurred on holiday abroad, fg1)
5. *'...but we sort of thought well the chemo itself is doing to debilitate him, do we have that When there is no actual benefit, or do we just say "Well I'm not bad now, I'll just stay like this". Eventually he decided to have the treatment: "Well I've got to take it haven't I...If I can stay a bit longer I'll take that decision"...So he had the 3rd treatment and that took a lot of getting over, but I think also by that time the disease was starting to progress.'* (Gillian, fg4)

### *Delay in diagnosis, inadequate medical knowledge and access to care*

Relatives reported that delay in diagnosis was a common experience, despite exhaustive investigations; uncertainty and/or false reassurances were difficult to live with. This caused extended periods of worrying for relatives (and patients) and undermined their expectations regarding professional competence, 5.6.1, 5.6.2. One wife described a 6 month period in which the diagnoses in sequence were atypical pneumonia; possible mesothelioma; normal scan; adenocarcinoma; and finally mesothelioma was confirmed. Another wife was convinced that the delay in diagnosing her husband's mesothelioma may have allowed the disease to progress to the stage of precluding surgical treatment<sup>51</sup> which she felt might have prolonged his life. Another wife reported that her husband received false reassurances twice prior to a biopsy confirming mesothelioma: a false negative biopsy report followed by a chest physician's opinion that a lump on his chest<sup>52</sup> at the biopsy site was probably scar tissue.

<sup>51</sup> Mesothelioma is only operable when it is localised to one area in one lung, the vast majority of cases have progressed beyond this at the time of diagnosis and surgery is never curative.

<sup>52</sup> Mesothelioma can spread down tracks formed by insertion of instruments for pleural procedures and results in chest wall swellings that are often painful. Prophylactic radiotherapy is recommended to reduce the risk of this occurring (BTS, 2000)

This wife reported feeling that the chest physician had failed them: she believed that an earlier diagnosis would have enabled her and her husband to spend a last holiday together. Grace, (fg3), also described inadequate medical knowledge: her husband's pericardial effusion<sup>53</sup>, a recognised complication in mesothelioma, was not diagnosed by the oncologist but later diagnosed by a cardiologist when it required emergency intervention, 5.6.3.

Three participants recalled knowing more about mesothelioma than some doctors: one wife, (Jean, fg5) told how her husband had undergone several unsuccessful and, in her opinion, inappropriate attempts at pleural aspiration although he had previously undergone pleurodesis<sup>54</sup>. Others described doctors quizzing them about their own sources of information. However participants acknowledged, with hindsight, that mesothelioma is relatively rare and can be difficult to diagnose. One relative described correcting a consultant who tried to assure her that asbestos hazards were only recognised recently – she was angry that he appeared to be ill-informed, 5.6.4.

Lack of knowledge may have led to inappropriate management in some cases although this may reflect concerns around current hospital admission procedures<sup>55</sup>. A daughter reported that when her elderly mother was admitted with a heart attack doctors initially appeared to take the situation seriously but lost interest once they realised the significance of mesothelioma, 5.6.5. Another problem related to admission procedures that treat all admissions as new cases: one wife, (Jean, fg5), described how on each of four admissions due to recurrent pleural effusions her husband was delayed in the Medical Admissions Unit whilst duty doctors excluded other more common diagnoses; she had known the diagnosis and felt that her husband should have had open access to the respiratory ward where his condition had been understood, 5.6.6.

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<sup>53</sup> Pericardial effusion: an accumulation of fluid around the heart causing impairment of cardiac function due to tumour invading the pericardium and producing fluid.

<sup>54</sup> Pleurodesis is a procedure that causes adhesion between the pleura and the inside of the rib cage thus obliterating the pleural space and preventing, or at least reducing, recurrent pleural effusions. Pleural aspiration is not usually attempted in patients who have had pleurodesis unless the pleurodesis has been unsuccessful.

<sup>55</sup>. Patients with medical emergencies are taken into a Medical Admissions Unit for assessment prior to transfer to an appropriate ward – the emphasis is on clarifying the nature of the acute problem and stabilising the patient's condition.

### **Box 5.6: Delay in diagnosis, inadequate medical knowledge and admission procedures**

1. *'I think as a professional he should have made an accurate diagnosis, and it's his responsibility, my husband was under his care.'* (Gillian, fg4)
2. *'We aren't professional, not medical people, and yet in my experience, people dealing with specific areas of the body such as the lungs, they must know the symptoms [of mesothelioma], my mother had every single symptom of mesothelioma and yet...'* (Joy, fg6, upset at the delay in diagnosis re her mother)
3. *'...they found out that it was fluid round his heart, his pericardium, and the oncologist said "I think it's just an infection" ...got him across to the consultant cardiologist...He said "I can tell you that it's the mesothelioma that's spread" and then he had to have a needle into his heart to remove the fluid...Even the consultant, the consultant physician at (the local hospital), was not that au fait with mesothelioma. When I went in armed... with all this information off the Internet, he was more interested in where I got it from and the websites!'* (Grace, fg3)
4. Sheila: *'.....The first appointment we had with Dr S, he spoke to George, how did he feel? And all about treatment and the rest of it, and he'd hardly anything to say. I said 'I would cut their heads off', he said "Pardon?" I said 'I would cut their heads off, for what they'd done to him.' He said "Well they didn't know till about 1966" I said "Come off it, they knew it caused cancer even though they didn't know it caused mesothelioma". But apart from that he was excellent, but I still can't get my head round that.'* (fg2)
5. *'And I said to the doctor that came "My mum has mesothelioma". (He said) "That's not the problem we're dealing with, we're dealing with a heart attack, we don't want to know about that...but I just got the feeling that because my mum had got mesothelioma and there was no cure for it, they weren't bothered.'* (Janet, fg3)
6. *'I don't know why they can't have a fast track method of getting these patients to the source of their treatment without all that.'* (Jean, fg5)

### *Dealing with doctors and nurses*

Good relationships with professionals were highly valued by all the participants but recollections of difficulties with healthcare professionals arose in all the groups. Concurring with findings from the patients' interview and medical notes review<sup>56</sup> data, relatives reported that most GPs had referred patients rapidly for investigations and supported the families throughout the illness. One couple (Dora and her husband Don, both fg2) were in a unique situation because they had each lost a parent with mesothelioma. They contrasted the care given by two different GPs: one had been 'excellent' but the other GP had seemed uninterested in his patient and had to be 'forced' into visiting her. They recalled his behaviour as inexplicable knowing that he worked at the local hospice and

<sup>56</sup> Chapters 4 and 3 respectively

they subsequently changed practices to register with a GP whose own father they knew had died due to mesothelioma, 5.7.1.

Relatives described problems when their understanding of the situation seemed at variance with the actions of doctors, 5.7.2. For example, they reported frustration about seemingly futile treatments when patients were, to them, obviously dying: one relative recalled her husband was given lipid-lowering medication on the day he died:

*'Did it matter his cholesterol was up?'* (Jean, fg5).

However relatives also expressed their understanding of the complexities of decision-making when only marginal benefits could result and the pressures on both patients and doctors to 'clutch at straws', 5.7.3

Nurses, particularly clinical nurse specialists, were greatly appreciated for their professional care and kindness, with just three exceptions reported, 5.7.4, 5.7.5. In one case a wife reported her anger at the way in which a hospital nurse had attempted to exclude her from her husband's care; in another case a Macmillan nurse had reportedly persisted in trying to persuade a patient to be admitted to the hospice against his wishes and had also appeared to exclude the daughter from the situation. As mentioned earlier, one family cancelled further visits from a Macmillan nurse who didn't appear to know anything about mesothelioma, furthermore she had suggested a wheelchair which was clearly impractical given the design of the house.

### *Dissatisfaction with the healthcare system*

Inefficiencies around obtaining results of investigations and inadequate follow up arrangements were recalled as sources of stress. Several participants worked in the NHS and reported using this advantage to achieve faster access to information and treatment by directly contacting consultants, chasing up appointments, and accessing other healthcare professionals for support.

Most relatives reported that they perceived it as their responsibility to obtain, monitor and often to administer medication. Difficulties were recalled with inflexible GP repeat prescription procedures and the apparent reluctance of some doctors to prescribe morphine, particularly when the patient was not

known to them, 5.7.6. Lack of continuity of care, particularly out-of-hours, and not knowing who to contact or who was in charge were reported as problems by several relatives. Out-of-hours arrangements for primary care caused great distress to one participant, a nurse, who found NHS Direct<sup>57</sup> unhelpful when she rang them as her father was dying, Box 5.8.

A common practical problem was difficulty finding a parking space near the hospital when the patient was severely breathless. Once inside, long distances between different departments caused distress for some patients and their relatives. As reported in the medical notes review, Chapter 3, some hospitals were up to 80 miles from patients' homes and three participants commented on lack of consideration for relatives living at a distance: one wife drove for 90 minutes each way to see her husband every day because although accommodation was available, for a charge:

*'There was no point in staying because you couldn't get in until 2 o'clock, so... all morning you'd be wandering about. (Jean, fg5)*

Two relatives told of contrasting experiences with the same hospital: one had nothing but praise for the hospital and the care received; the other reported being given no information about meals or visiting times and almost as soon as her husband arrived she recalled she was told to leave *'...because it was the patients' rest period'* (Dora, fg1)

Three participants reported that they were still considering making formal complaints, none had complained earlier. One wife was contemplating a complaint concerning the way in which her husband was told the diagnosis on his own, ahead of the appointment that had been made for them to receive the diagnosis together. She explained that she had needed time to calm down before she could proceed. However she may have been too busy and concerned about her husband at the time to pursue a formal complaint against one of the doctors responsible for his treatment. With hindsight, she acknowledged that raising the issue might help others although she emphasised that it was for her own sake and would help her *'enormously'*. One other relative was considering making a formal complaint about the way in

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<sup>57</sup> NHS Direct is a national telephone service that patients can access for advice, in this case the service dealt with out-of-hours calls to Primary Care, replacing the former arrangements that GPs provided out-of-hours cover prior to the new GP Contract, 2004.

which a procedure was carried out which caused her husband unnecessary pain. She reported that her husband had suffered complications from pleurodesis during an earlier admission, prolonging his stay from three to 7 days – perhaps this had made her less tolerant of subsequent problems<sup>58</sup>, Box 5.8. In the third case the GP had subsequently encouraged a patient's daughter to make a formal complaint about the response they received from NHS Direct when her father was dying, Box 5.9. This daughter explained that the family had not felt able to complain at that time but might do so in the near future.

Although most reports regarding hospices were very appreciative, three relatives recalled dissatisfaction. One patient and his relatives had apparently felt pressured to accept hospice services that they did not want, and were upset by the staff who they perceived to be patronising. In another hospice, Jean (fg5) described how her husband had been unhappy with his room which was dark and overshadowed by trees, and he was distressed at not being allowed to handle his own medication. Two wives complained about communication issues: with ironic humour, one wife recalled a hospice doctor's questions to her husband about his feelings as inappropriate and intrusive, this doctor had also made the remark about '*feeding the tumour*' mentioned earlier in the communication section:

*'That's wonderful isn't it? Absolutely wonderful... So I took him [her husband] a bottle of whisky in!'* (Jean, fg5, laughing)

The other wife, Dora, (fg1), had been very upset to be told by hospice nurses that her dying husband only became distressed when she was visiting him. In the group she disclosed, for the first time, that her husband's distress was because she would not assist his suicide which they had agreed before his admission – she had not explained this to the hospice staff at the time and their remarks continued to distress her<sup>59</sup>.

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<sup>58</sup> See Methods chapter for an account of the discussion that I had with Jean following the focus group.

<sup>59</sup> Discussed later in section 3, 'In it together'.

### Box 5.7: Dealing with doctors and nurses and dissatisfaction

1. *'...really he should be caring for his own patients and not the hospice...whereas (other GP), she'd just call in...and I think if he'd have just called in it would have put my Mam's mind at rest. You know, we had to force him into coming to see her'* (Dora, fg2)
2. *'Why were they giving a dying man all those pills? Why? Did it matter? That morning they'd been trying to force them down his throat when he was actually...(dying) but with a 7lb thing in your chest like that,<sup>1</sup> how could you swallow pills? What difference does it make?'*(Jean, fg5)
3. *'I thought "Why are they doing this? Why don't we just let it take its course and enjoy being well? ...But I think sometimes you feel under pressure to do it, it's like a carrot and stick scenario. If the treatment's there I think a lot of people feel compelled to have it.'* (Gillian, who by her husband's third session of chemotherapy, realised its futility and opportunity costs, fg4)
4. *'I could go out and I could cry – she'd hold my hands or she'd put her arms round me, give me a cuddle, and I could cry out in them grounds, then go back ... (the nurse) came in her own time, late on at 11 o'clock at night sometimes'* (Pam, fg2, describing her 'special' district nurse)
5. *'The Macmillan nurse that we had was no use. She didn't come for 3 months... she brought some forms for Attendance Allowance, and I said "Oh thanks for that, I'll fill them in" and "Oh no, I shall do that" she said, and I felt she didn't think I was capable of filling a form in...and she said to my Mum that I was too possessive of my Dad. And she didn't appear again for 3 months. She didn't offer anything, any suggestions or even any sympathy... I understood the Macmillan nurses were supposed to treat the whole family? And do you know when she next came? ...3 months later...2 days before my Dad died, and she stayed for 1¾ hours... And then my Dad died on Christmas Day and we never heard again from her... Mum thought at least she could have rung .'* (Amanda, fg1)
6. *'...and it looks awful...to a doctor you look like a lay person telling the doctor what to do, But you know about it, you can then speak up, and I had to prove who I was, 'cos I could be anybody going in,.'* (Pam, fg2, recalling trying to obtain a repeat morphine prescription from her local hospital, prescribed but not supplied by a distant hospital.)
7. *'...he was whipped back into hospital again and he kept on vomiting...and the man sat next to Jimmy had said (whispering) "He's been like this all day". And of course I went in (behind the curtains) and this nurse said "Do you mind? I'm seeing to your husband, he's being sick." I said "I'm well aware of that and yes, I do mind!" I thought it's my husband, he's dying, you know. ...I was so upset I couldn't speak, I couldn't even go and tell her.'*(Pam, fg2)

### Box 5. 8: 'Do I have a complaint?'

*'Well the first time he went in, obviously his lung was practically to capacity, and it is our opinion that the man who did it was learning. He had Dr A with him, but this man, you've never seen such...it was like the tubing and the way it was put and everything, it was like oh I don't know, an engine. And the nurse came along and she had a look and she said "Dr F wouldn't have accepted that". Now Sam was not a complainer and he said it was bad. Now for him to say it was bad, it was...Pain yes, bad. ...he was done on the ward, the other patients said to me "I don't know how you put up with that" and the doctor had had to say to the person doing it "Just be gentle"-obviously he'd just gone...and out had just come a lungful! And this pipe was stuck all round his hand. Another thing I would have liked to have killed the man for, when he took it off he ripped the plaster off and he took 2 lumps of skin off his chest with this plaster, just ripped it off, "Oh I'm sorry!" ...Do you think I...Do you think I have a complaint?... I've waited this time because I didn't want to do it unless I could do it without getting emotional. It wants to be factual, and up to now I couldn't have done it, because you know it's too close.'* (Jean, fg5, deliberating whether or not to make a formal complaint about her husband's care)



### Box 5.9: A problem with NHS Direct

One relative, Amanda, (fg1), described the problems she had in accessing the emergency out-of-hours GP service when her father was dying just before midnight on Christmas Day. She rang the surgery and a recorded message gave her another number to ring – she subsequently discovered this was NHS Direct, 70 miles away from her home. She gave her father's details and said that he couldn't get his breath. The receptionist said that she'd send an ambulance. Amanda was not happy with this as her father had not wanted to go into hospital and so she again asked to speak to doctor. At this point the receptionist wanted more details, asking seemingly endless questions about the exact details of names and dates of birth:

*'...I told her he was 80, I didn't know what year, I was becoming very frustrated. I told her my father was dying and put the phone down'.*

Amanda recalled her father being very scared, his condition worsened rapidly, his breathing slowed and then it stopped:

*'I got him onto the floor... I put a pillow under his head. 2 minutes later I rang back, same number, and said they'd have to send a doctor now, my father had died.'* (Amanda, distressed fg1)

Amanda, her sister and their frail elderly mother were all nurses – they did not panic in this situation presumably as a result of their training but they felt that the NHS Direct service failed them.

## 5.4. Caring in the family setting

### *In it together*

*'He only wanted me to look after him.'* (Grace, fg3)

All the 17 participants had been closely involved in the care of the patient and they recalled how they faced the illness together, either husband/wife in 14 cases or parent/child in three cases. Bereaved spouses told how, as couples, they faced the illness following their usual patterns: some discussed things openly if this had been the style of their relationship, others built upon clues in conversation and behaviour as mentioned in the first section on awareness. Relatives recalled that the patients had 'set the scene' in demonstrating or expressing how they wanted the family to deal with the situation. 'Normalising' the situation was expressed as important for many couples; with hindsight some relatives reflected that this approach had helped them to cope until the disease impact was unavoidable although the 'pretence' involved created tensions. Another source of stress was the conflict between 'dealing with the now' at the same time as 'dealing with the future', some relatives recalled feeling guilty and selfish, thinking ahead while their loved one was still alive.

Participants described how the situation resulted in altered roles within their relationships which caused distress and sadness for both husbands and wives. They described how their loved ones, as in the patients interviewed<sup>60</sup>, had been physically active in all but one case, who had Parkinson's disease, and it appeared that both husbands and wives had enjoyed traditional roles and responsibilities in their marriages which were challenged by the illness. Relatives described increased intensity in some relationships due to the proximity of death.

Wives told how they had respected the wishes of their husbands in the three cases in which their husbands had specifically preferred them to manage without outside help, although this had actually increased the burden of care and responsibility for them and added to social isolation. Other relatives described sensing that the patients needed explicit assurance that they would care for them. Standing by and watching a loved one suffering was reported as hard to bear. Relatives told how visible loss of physique and strength upset them and reinforced the seriousness of the situation; this concurred with the distress expressed by the patients interviewed in Chapter 4. Not all the patients had dramatic symptoms. Some, like Sheila's husband, steadily lost weight and vitality but he, and others, tried to alleviate distress with humour.

Two wives disclosed that their husbands had asked them to assist their suicide, this had caused huge anxiety at the time; both wives told that they continued to feel they had let down their husbands by not helping them to die. In one case the GP had confirmed the man was dying and commenced medication to ease his distress; in the other case, the man (Mr I) was in a hospice and was so upset when his wife refused to help him die that he didn't speak to her during his final week.<sup>61</sup> This wife reported she had felt unable to assist him to die because he was in a hospice – she wondered how this might have differed if he had been at home<sup>62</sup>.

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<sup>60</sup> See Chapter 4

<sup>61</sup> Her husband (Bob – Mr I) was interviewed in this study just 6 days before he died and he did not make any mention of wishing for assisted death or wishing to die in the interview.

<sup>62</sup> See Methods chapter re information given to all participants after the focus groups..

### **Box 5.10: In it together**

*'...while ever he was well he kept me going, and I think I got to a point that I think I thought he was going to stay like that, that he was never going to be well again, you know, but he was going to stay at that stage and it wouldn't go any further...I knew it was going to happen but...'* (Mary, fg3)

*'I think I was upset but I was also very frightened, really frightened... I'd always had him there as a back-up and the longer it went on the more frightened I became. You know, waking up on an evening with, like, panic attacks and thinking "How am I going to cope without him?".'* (Mary, fg3)

*'He didn't like to see me doing his jobs - like put that wheelchair in the car. You could see by the look on his face he didn't like it, and he used to keep saying "I'm sorry I can't do more"'* (Jean, fg5)

*'I didn't go to bed for 11 weeks. But he said to me "Please don't get anybody in, please" As ill as he was, he said "I don't want anybody going: "Well are you all right?" ... "Poking her head around the door" (Pam, fg2)*

*'I didn't recognize my own husband from the back 'cause he was losing weight so rapidly.'* (Pam, fg2)

*'And he just got weaker and weaker, and you could actually see the tumour under the skin, and he'd say "Look at me, I'm skin and bone. Fancy ending up looking like him" (That's the cat!)'* (Sheila, fg2)

*'He actually asked me to help him to die towards the end and I said "I can't do that"... the doctor fortunately came and I spoke with her and she said "It's time for a syringe driver now".'* (Grace, fg3)

*'What they didn't know was that Bob and I had made a pact that I would give him -I had quite a lot of drugs – that I would finish him off (sobbing), and once he went to the hospice he'd asked me to do it. ... (doctor) had spoken to me, I realised there was going to be the inquest anyway, but that wouldn't have bothered me, I couldn't have cared less if I'd gone to jail. You live with somebody for 40 odd years and you couldn't care less, if they go you couldn't care less what happens to yourself. Bob got very annoyed with me, and a week before he died he stopped speaking to me, because he turned round and said to me "You wouldn't see a dog suffer like this". (Dora, fg1)*

### **Spoilt plans**

Living with mesothelioma often necessitated practical changes at home, particularly as the disease progressed and caused increasing physical limitations for patients. In one case this caused major upheaval: Edna (fg 4) and her husband were advised to move into a bungalow by the clinical nurse specialist because she felt their house, the wife's family home for 46 years, would not be suitable as he deteriorated, 5.11.1. Many families brought a bed downstairs to make life easier as breathlessness and weakness reduced mobility.

Several couples went away on holiday to familiar places even when symptoms were a problem, others did not have the opportunity as the disease progressed

too rapidly, 5.11.2, 5.11.3. Those wives who were able to have holidays with their husbands told how spending time in places associated with happy memories gave them pleasure whilst living with the knowledge of impending death. An inaccurate prognosis of two weeks when the patient eventually lived for 13 months caused considerable problems including financial strain for one couple. When her husband did not die within two weeks, following a large and expensive farewell party, the couple (Dora, fg1, and Bob, patient interviewed) embarked on an extensive series of foreign holidays to the point of financial embarrassment. Dora reported with delight that they had no insurance cover reflecting the 'devil may care' attitude this couple adopted when he lived far longer than predicted, 5.11.4. Unfortunately their last holiday was disrupted when he developed a steroid-induced psychosis as reported earlier<sup>63</sup>. One son reflected sadly that the assessment of 'years of life lost through the illness' as part of the compensation calculation had highlighted the family events that his father would miss, 5.11.5.

#### **Box 5.11: Spoilt plans**

1. *'...and he just sat down in the chair...breathed a sigh of relief and he said "Oh well, we can relax now can't we?" and I thought "Can we?"(Edna, fg4, describing her reaction when they finally moved house)*
2. *'...and he was struggling. I said "Do you think we should go home?" and he said "No, I'll be all right" so we stuck the week out' (Grace, describing her husband becoming unwell on holiday, fg3)*
3. *'Yes...we weren't able to have a holiday because by the time it sort of came up to us getting round to it my husband was too ill.' (Gillian, fg4)*
4. *'For 2 weeks everybody had parties for us, every day, parties, going away parties, like wakes...everybody wanted to give us a party, all the kids were there, they were coming from all over the country... then the end of the 2 weeks come, and you've not died. You feel then, a fraud, don't you? That's how me and my husband felt, as though we'd lied to people. You know, he should have been dead, that's what we'd been told...We packed a lifetime into the time we had left...Bob and I had so many holidays, we only used to come home to wash my knickers and then we were away again! Backwards and forwards all the time... No insurance, you know!' (Dora, fg1)*
5. *'...my dad's been dead 2 years now...and he's supposed to have another 2 years left. Well in that time he's missed his grandkids, 2 of them, one starting nursery and going on...he should be looking after my mother now. You know, my babby walking and going to school, all that's gone.'(Andy, fg1)*

<sup>63</sup> See medication section in Chapter 4, p155.

## *Lynchpin of the family*

Some relatives reported pre-existing and competing carer responsibilities, usually concerning elderly parents, but Gillian, (fg 4), had children aged 12 and 14. She told of the difficulties trying to maintain their usual routine while caring for her husband and that tensions sometimes developed when he was less tolerant than usual with their behaviour. She recalled deciding what and when to tell them about their father's illness particularly hard, trying to balance her desire for them to lead their normal lives with the need to prepare them for his death, 5.12.1. One participant described caring for her daughter, husband, terminally-ill father and also her elderly mother with memory problems; another was the main carer for her demented father whilst also looking after her husband. Others found that they were leant on by the extended family, 5.12.2. Although relatives told how they sometimes could rely on family members, caring usually fell to the closest relative, either the wife or an adult child. Practical help, for example, moving the bed downstairs, help with transport or childcare, was particularly appreciated but conflicting demands from other dependents caused irritation and sometimes resentment. Several participants agreed that the patients did not seem to appreciate the demands on the carers: one participant described how her mother, a retired nurse, appeared reluctant to 'bother' ex-colleagues '*because they're so busy*' which put extra strain on the family, 5.12.3.

### **Box 5.12: Lynchpin of the family**

1. *'...if I was to say to my children, "Your Dad's going to die" they'd be expecting it tomorrow, and we sort of left it until he was in the Hospice, and I said "You know your Dad's not going to get any better? You know what's going to happen, don't you?" and Emma said "Yes, he's going to die" and I thought well "Is she thinking he's going to die tomorrow? Is he going to come out?" you just don't know...I was sort of taking the children home, my parents were looking after them, I were going back then coming back home...but from his mum "Oh my God he's gone into the Hospice, he's going to die!" I says "Look, he's only gone in because he's having trouble breathing, he'll get his medication sorted out, they might get some oxygen at home, he'll come home". I felt I were having to be caring for everybody else' (Gillian, fg4, describing supporting her children and mother-in-law).*
2. *'I'd got this burden sitting on my shoulders to tell my 3 brothers and my sister [that their father had only got 4 weeks to live]... and at the same time to put a brave face on for my Mum and my sister was trying to convince me that everything was OK because he'd still got his appetite.'* (Moira, fg6)
3. *'And Mam sort of pushed them (the community nurses) away "I know how busy you are, I don't need your help, you've got other patients to see" so they'd left it up to her...so we didn't like to ring.'* (Amanda, fg2)

## *Physical care*

Relatives described involvement in physical care: for the majority, general nursing care in terms of nutrition, medication, hygiene and comfort were the essential tasks. These tasks were more difficult in the face of uncontrolled symptoms. In some cases relatives described their anxieties in trying to assess the severity of symptoms when the patient was stoical to the point of not admitting any discomfort, 5.13.1. Relatives described how lack of knowledge of what to do caused anxiety, particularly when patients were severely breathless, although most had medication available for pain, 5.13.2. One participant, (Gillian, fg4) recalled a frightening episode in the early hours of one morning when her husband was leaning out of the bedroom window gasping for air. In common with reports from the other relatives it was she, not her husband, who decided to call for their GP.

Many relatives reported acquiring nursing skills such as dressings and managing complex medications: for example, Pam, (fg2) recalled that her husband had a drain in his abdomen that needed frequent dressings but which often blocked and leaked profusely, causing them both distress, 5.13.3. Relatives reported sweating was a major problem; this often involved changing the bed every day entailing time-consuming physical effort, 5.13.4. Most relatives organised and administered multiple medications, and also looked out for complications. Relatives described their desperation in the face of lack of effective treatments, two wives reported turning to complementary therapies. When one man developed a steroid-related psychosis abroad his wife reported how she had to ensure that his condition was understood in a foreign hospital and then had to supervise him on the flight home. The physical burden could be substantial: in two cases it included lifting oxygen cylinders unaided. One wife described her total exhaustion when her bedridden husband lived weeks rather than the predicted few days. In common with other wives, she reported regret at having agreed to his request to care for him alone: she recalled how her husband repeatedly rang his bell to call her back up to his room, seemingly oblivious of the other demands on her time, 5.13.5. With hindsight, although joking that this had given the community nurses an easy job, these wives acknowledged that they had not previously appreciated the demands of the carer's role, 5.13.6. Several relatives reported having an enormous personal

responsibility for providing the best care and comfort for their husband or parent, at times turning to unconventional treatments, 5.13.7, 5.13.8.

#### **Box 5.13: Physical care**

1. *'I don't know how much pain he was in but we had the Oramorph as well as the Morphine. So that if I thought he needed it he used to get it: "Open your mouth"'* (Jean, fg5, who had to use her judgement as her husband would not admit to having pain)
2. *'...and I think he were frightened. And I were frightened, I thought "What will I do? Will I Ring for an ambulance? Will I do this? Will I do that? What if he passes out?" She phoned for the out-of-hours GP who visited and tried to reassure her: "The GP says "Don't worry, if he passes out he'll just come round again in his own time" because that was what I was worried about, I said "What if he passes out because he can't breathe?" he says Well he might pass out but he will come round again once everything...it's panicking that's mainly (the problem)."'* (Gillian, fg4, describing her fears and decision-making)
3. *'...it was oozing from the suture site, it was also clotting, so what was going on in bed, halfway through the night I kept on having to sort of give it a little kink to get the clots through...And while you were doing that it was pumping out the side... down the side of the sheets.*(Pam, fg2, describing care of her husband's abdominal drain)
4. *'I mean on a morning I could be soaked as well, laid by the side of him, I could have wrung the bedclothes out, and every morning the bed had to be stripped. I know it sounds a silly thing, but it was a very big problem'* (Mary, describing her husband's sweating, fg3).
5. *'...he'd be ringing the bell and I would be back up again, but I'd give anything to hear him ring that bell again now. But he was very demanding... he was on oxygen and I was humping oxygen cylinders up and down stairs, he was getting through 4 cylinders. And just trying to sleep and be there, I mean sometimes I didn't get any breakfast till nearly lunchtime because I was having to get him washed and then trying to get him out of bed, and we had a commode wheelchair, pushing into the bathroom...'* (Grace, fg3, describing her exhausting schedule)
6. *"What a wonderful job you're doing" you know. (laughing) They said it was the best job they had.'*(Pam, fg2, describing how the District Nurses praised her care of her husband)
7. *'I found that's what I felt, when somebody is ill they're vulnerable, and it's a bit like, you know like you are with your children? You know, you get into that defensive mode, you know: "I'm looking after this person, I want everything to be right".'* (Gillian, fg4, describing her sense of responsibility)
8. *'I phoned friends all over the world, put him on Echinacea ...I didn't want him to catch anything else, didn't want him ill, wanted to keep him alive as long as I could... You're only supposed to give that short-term. I gave it him it for the year because...'* (Dora, fg1)

#### **Emotional labour**

Keeping up a cheerful pretence in order to avoid adding to the patient's distress was recalled by many relatives and at times they admitted feeling guilty if they broke down in front of their loved ones when the strain became overwhelming. However, care was also reported as *received* by the bereaved spouses during

their caring role: some ill husbands had been able to express their appreciation of the care given and often to reflect on happy memories that they had shared. Relatives also reported that they appreciated expressions of concern from some healthcare professionals who seemed to have an understanding of the situation from the carer's perspective and did not solely concentrate on the patient's problems.

### *Experiencing the death*

Many of the deaths the relatives had witnessed were reported as very distressing and were recalled in detail, Box 5.14. Severe breathlessness, confusion, hallucinations, terror, uncontrolled agitation and intense pain were described by the relatives, 5.14.1-3. At times recollections of distressing deaths of loved ones brought tears and other group members expressed sympathy and words of comfort.

There was one exception: Jacky, (fg6), expressed satisfaction and pride that she had been able to care for her elderly mother at home. In this case the patient had been elderly, fully aware of the diagnosis, the symptoms had been well-controlled, she was not distressed and was philosophical about dying. Jacky described the death of her mother as '*wonderful*' and that she '*would not have missed it for the world.*'(Jacky, fg6) <sup>64</sup>

Bereaved relatives recalled that most of the patients had wished to die at home, but the majority had died at home or in a hospice, contrasting with the findings of the medical notes review, p 124. Care at home in the dying phase usually relied on District Nurses and, to a lesser extent, Macmillan nurses. These community nurses were particularly appreciated and warm personal relationships that went 'beyond the call of duty' gave enormous support and comfort. There were some examples of good practice where services enabled patients to die at home if that was their wish: Pam, (fg2), praised the 'Home to die' service, in Scotland, describing it as a '*lifesaver*' for her. Reasonably acceptable deaths according to the relatives occurred peacefully, either at home or in a hospice, with effective medication if necessary to control symptoms.

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<sup>64</sup> This group, fg6, also heard of the most distressing death – that of Lynn's husband as in the Vignette 5.1, p 192. As described in the Methods Chapter, Jacky, whose account followed Lynn's in the group, was at pains to console Lynn and express her sympathy, then adding that it might help her to know that not all deaths are so terrible.



several cases confusion and hallucinations at the end added to relatives' distress, medication was frequently blamed for these problems, 5.14.3.

Four participants reflected that their relatives may have been particularly scared because they had heard reports of distressing deaths due to mesothelioma. Distress also related to unexpected deaths when rapid deterioration was hard to believe. Mary (fg3) recalled how her husband, somewhat reluctantly, was admitted to the hospice for symptom control and expected to go home again but he deteriorated rapidly and died in the hospice two weeks later. Relatives expressed sadness and regret when circumstances prevented death occurring at home: Mary, whose husband had wished to die at home but deteriorated suddenly and died shortly after admission to the hospice, regretted the loss of physical intimacy:

*'...and I really regretted that because he would have loved being at home, you know....Even just to be able to lay on the side of the bed with him'*

(Mary, fg3).

Many months later she remained shocked at his sudden death, her husband had been playing golf a few days before hospice admission.

#### **Vignette 5.1: A distressing death**

Sue, (fg6), described her husband as a *'phenomenally fit man, obsessive about DIY, he could do anything'*.

After 6 months of repeated investigations and misdiagnoses mesothelioma was confirmed. He became very depressed and particularly upset that he could not do the physical activities that he loved. Due to her own ill-health, Sue could not continue to care for her husband at home when he needed constant nursing. Her husband decided to go into the hospice when he could no longer move without assistance. On 2 occasions sedative drugs caused paradoxical effects – he had become agitated and confused. Although they were repeatedly told that he might live 3 to 4 years, he died 4 months after diagnosis.

On admission to the hospice Sue was advised to go home to get some long-overdue sleep:

*'That is the biggest regret of my life, I was prompted to decide to go home to sleep...when I got back in the morning the same thing had happened again [agitation due to sedative medication] ...he was so agitated and then he coughed – I was there by myself and this vile black substance came out of his mouth...I thought it was a haemorrhage and called for help. It kept coming every time he coughed. At one stage 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.'*

### Box 5.14: Distressing memories

1. *'...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)
2. *'...and he felt he was being pushed under water and he just couldn't breathe.'* (Grace, fg3, who was clearly upset at this painful memory)
3. Edna was grateful that she was able to stay overnight in the hospice and that she and other family members were with her husband as he died. She had hoped to take him home from the hospice but he deteriorated quickly at the end and plans were cancelled. She described his death as 'drugged, in a morphine sleep' at the end but earlier he had been very confused and hallucinating: he started searching the bedclothes for babies: *'...and the nurse came and I said "What do you know, he's got 2 babies on his bed" so she just says to me "Have you ever had any miscarriages or lost any babies?" and I says 'Yes, I lost 2 babies in miscarriage" and she says "He's got them".* This presumably was an attempt of the nurse to comfort her with a simplistic explanation. it had the opposite effect because Edna interpreted this as meaning his death was imminent. She told how her husband then started shouting out, believing he was back in Japan at the end of the Second World War *'...and the language was getting a bit rank! I thought "Oh my God, quiet, Ernie, you're not in Singapore now! (fg4)* Although Edna told this story in a humorous manner it caused concern to other members in the Group and her humour may have been an attempt to minimise her own emotional distress.

### *Impact on carers' health*

The physical burden could be very heavy as described earlier. One wife described feeling inadequate and guilty because pre-existing arthritis prevented her caring for her husband as she would have liked. Many participants recalled how they had been able to carry on with '*a sort of false energy*' but then suffered from overwhelming exhaustion when their loved ones died.

Participants also described living with constant anxiety, whilst trying to keep up a cheerful appearance for their ill relatives. The anxiety sometimes led to panic attacks and often carried on into the night, insomnia was common. Sleep disturbances sometimes continued after the death no matter how exhausted the carer felt. However, Pam (fg2) recalled that although she slept on the settee for 11 weeks with frequent interruptions to attend to her husband in the same room, she did not really feel the need to sleep at the time and was alert all the time in case he needed her:

*'...it was as if somebody had given me an injection to keep me awake.'*

The stress of the situation resulted in three carers starting to smoke again, one had stopped again by the time of the focus group, another participant hinted that she had tended to turn to alcohol for comfort. Apart from working full-time and supporting all the family, one carer recalled being very stressed by also trying to manage legal issues (both connected and unconnected with her father's illness) because her elderly mother was unable to understand them.

The relatives often felt alone with their problems, and as shown earlier, they acknowledged that mesothelioma is relatively rare and that there are no public figures acting as 'champions for the cause.' In the second focus group two participants expressed feelings linking isolation with the stigma associated with terminal illness and fears of contagion.

*'It's as if you've got smallpox or something.'*

*'Exactly right, it's as if you're the one with some incurable disease, a leper, and it's catching.'* (Susan and Pam, fg2)

### *Grieving*

The focus groups were not designed to explore the experience of bereavement but, as the participants were all still grieving, it featured in the discussions. Relatives described their reactions to the death of their loved ones and the ways in which being bereaved had affected them, 5.15.1. Many recalled being physically and emotionally exhausted at the time of the death due to the burden of care that fell mainly on them alone, as described earlier. The three exceptions related to the carers for a man who had only been in bed for a few days before he died, an elderly lady whose illness caused a slow decline in her health but without severe symptoms and who had a 'good death' at her daughter's home and an elderly man who was in hospital throughout his brief illness. Relatives reported that the rapid disease progression and the demands of caring did not allow any time to think or plan ahead in most cases; these factors may have prevented anticipatory grieving which is believed to help in grief resolution (Sweeting and Gilhooly, 1990).

Grieving relatives described a sense of isolation that was exacerbated by the feeling that few people knew what mesothelioma was: they contrasted this with

media accounts and public knowledge of the common cancers. This made it difficult to talk to other people and was perhaps also related to the notions of contagion and stigma referred to by two participants. Some relatives found it difficult to cope with suddenly being alone because they missed all the healthcare professionals visiting as well as being without their partner. Those relatives who had received bereavement care, usually through their involvement with hospices, found it very supportive. One widow felt that this type of support should be available and offered to every bereaved person, Box 5.15. Many relatives described how they were still involved in compensation claims as detailed in the next section.

Anxiety and insomnia were reported as common in grieving relatives. In some cases this was a continuation of problems during the time spent caring but the focus had altered: one widow worried that she might become ill and have no one to care for her, another sobbed as she recalled how she always relied on her husband for support when she had any worries. Only one relative, a daughter, reported still feeling angry – she was a nurse and had felt let down by fellow professionals, (Amanda, fg2); although not said with anger, there were many remarks from participants about the injustice of asbestos-related diseases. Poor concentration was reported by two relatives, one declaring she felt '*brain dead*' and now had poor memory. Some relatives described making an effort to avoid depression by adopting new activities, in one case an Open University course. Others reported relying on family and close friends for support, none mentioned the church. Some relatives reported feeling guilty because they had not said all that they had wanted to say to their loved ones, the other group members reassured them that this was inevitable, 5.15.

### Box 5.15: Grieving

*'I miss him terribly, we'd been together 55 years...It's a long time (sobbing)...It's stupid, I didn't intend doing this.'* (Mrs E, fg4)

*'Yes, the cut-off point – Bob died, I came, saw (the doctor), saw the Coroner, saw everybody there, and yes, next day I'm on my own... and there's nobody and there's no help and there's nothing. Never thought I would take to my bed, took to my bed because I lived on my own, he's not there. You need somebody to see the bereaved widow or the next of kin, the person who lives with that person. You need someone there to be in touch, but without that person having to go to try to look for help... somebody should get in touch straight away and say...well "We've got a discussion group of other bereaved people, would you like to come along?" ...if you go to a doctor, and I went to the doctor and all the doctor could suggest was "You're depressed, you need tablets" but no, I don't need tablets.'* (Dora, fg1, with her thoughts on the support needed after a death)

*'I mean fortunately my local Hospice run a bereavement group for younger people and the Social Worker there invited me to go there, and I found that very helpful because as you say, it's talking about it that helps you to come to terms with it'* (Gillian)

*'You can talk to strangers but you can't say things to your family. I can talk to my family about most things but things that go through your head when you've just lost somebody, and you're frightened of upsetting your family...If you've got a professional to talk to who will know what you are going through is normal, you know, it's quite normal to feel like that. Perhaps you will feel that you're going mad. I was fortunate that I had that support, but I know not everybody does, but that's a general thing, isn't it, rather than mesothelioma? I think the one big point is this with the inquest, the post mortem.'* (Edna, fg 4)

*'The thing for me was I couldn't speak, right at the end.'* (Dave)

*'He couldn't say what he wanted to say, and it's always haunted him really.'* (Diane, Dave's wife)

*'Well we all have this guilt trip, it's awful really.'* (Pat)

*'I couldn't say what I wanted to say to my husband. You want to say it and you can't get it out, it's there, you want to say it to them but you can't say it. I told him I loved him, everything like that, but not the way I wanted...'* (Sheila, in discussion with other fg2 participants)

## 5.5. Socio-medicolegal issues

The issues covered in this section relate to the social and medicolegal contexts surrounding mesothelioma as they affected the focus group participants. Causation and attribution issues are followed by matters related to mesothelioma as a Prescribed (Industrial) Disease<sup>65</sup>.

### *Mesothelioma as an 'unnatural death'*

*'My husband was murdered'*

<sup>65</sup> As mentioned earlier, Prescribed Disease denotes a recognised disease caused by an occupation, in the case of mesothelioma it recognises causation due to industrial exposure to asbestos. Cases in which the exposure has been environmental or non-industrial are not categorised as Prescribed Disease and are not entitled to some related state benefits.

In contrast to the data from interviews with patients, (Chapter 4), the relatives expressed no doubts regarding the cause of the illness: they all believed that asbestos caused mesothelioma and articulated strong feelings concerning blame; three relatives stated their loved ones had been ‘murdered’, 5.16.1-2. Relatives reported outrage and pain due to knowing that their spouse or parent had died as a result of avoidable exposure to asbestos. Suspicions that commercial considerations rather than ignorance had delayed the introduction of safety measures were reported as adding to their distress<sup>66</sup>. Several relatives voiced concerns that risks were still being taken with respect to asbestos, particularly by ‘cowboy builders’, 5.16.3. In one case a hitherto unrecognised occupational exposure had been uncovered: Mary’s, (fg3), husband had been a public service worker in an industry in which asbestos exposure had not previously been considered. Mary reported that her husband successfully pursued the first claim against that public service and led the way for many subsequent claims. Some cynicism was evident and a sense that the participants had lost respect for authority because the statutory bodies had failed to protect the patients from health hazards at work. One relative regretted that her father did not have a coroner’s enquiry: with hindsight she realised that this would have publicised the fact that the responsibility was that of the local council for the sports centre where he had worked and been exposed to asbestos in the roof; she knew that although the council had temporarily closed the building to seal up the asbestos, it had since reopened.

**Box 5.16: Mesothelioma as ‘murder’**

1. *‘I honestly believe that my husband was **murdered**.’* Emphasising that point, Mary clearly held the industry responsible for her husband’s death:  
*‘Because he was, as far as I’m concerned he was murdered, through greed and neglect. To me they’re no different to drug dealers, because they wanted to leave the money through businesses and one thing and another, and they take that money and they don’t want to pay it out and they’ve murdered people along the way’.* (Mary, fg3)
2. From a different group, the same comment:  
*‘Well they were responsible, it’s actually, to me it’s like mass murder, isn’t it?’* (Pam, fg2)  
*‘Without a shadow of a doubt, yes.’* (Don, fg2)
3. *‘I do get angry when I read stuff in the paper now about it, and they’re still not doing as much as they should be about it. You know they’re still getting away with things.’* (Mary, fg3)

<sup>66</sup> The delay in implementation of relevant Health and Safety measures is described in *Asbestos Killer Dust* by Alan Dalton, 1979.

## *Medico-legal issues*

*'You must see a solicitor, you must make a claim'*

Three specific medico-legal issues were discussed in all the groups: State Benefits, civil compensation claims and the coronial investigation. Industrial Illness Disablement Benefit applies in mesothelioma due to asbestos exposure at work, in addition to the usual benefits available to people with terminal illness. Civil compensation can be claimed against an employer or employers who have exposed a worker to asbestos. Death due to mesothelioma is classed as 'unnatural' and as such has to be investigated by a coroner<sup>67</sup> who usually requests a post mortem examination, which the relatives cannot refuse, followed by an inquest in order to ascertain the cause of death.

Several relatives reported that the patients had been initially reluctant to claim benefits. The carers described how they had to negotiate this tactfully in order to achieve due financial assistance, this was at the risk of confronting the realities of the terminal illness and causing further distress for the patient. Relatives described their difficulties in negotiating the complexities of the State Benefits system, particularly when busy looking after a terminally-ill patient, and their additional anxieties regarding the civil compensation procedures. Relatives reported that they usually took the main responsibility for making these financial claims to avoid additional strain for terminally-ill patients. They recalled needing help, usually from Macmillan nurses, to complete complex benefit claim forms. Relatives reported being upset when patients underwent apparently unnecessary DSS<sup>68</sup> medical examinations causing critical comment from other group participants<sup>69</sup>, Boxes 5.17 and 5.18.

Some relatives revealed lack of information about State Benefits and gleaned knowledge from other participants. This led to some complicated discussions, sometimes adding to the confusion, but on other occasions prompting a decision to try to make a retrospective claim, 5.17.3 - 4.

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<sup>67</sup> Under English law the coroner is responsible for investigating all unnatural or suspicious deaths. In Scotland, the equivalent position is the Procurator Fiscal but the investigation is similar.

<sup>68</sup> Department of Social Security

<sup>69</sup> This requirement, supposedly to ascertain the medical condition of the claimant, has recently been removed from the regulations when a diagnosis of mesothelioma has already been confirmed.

### Box 5.17: State benefits

1. *'We could have been claiming Industrial Disease Benefit...about £114 a week, but we didn't know anything about that until much later...people need it explaining to them...you are busy 24 hours a day looking after a sick man...forms are not the thing that you're going to think about.'* (Mary, fg5)
2. *'We took the government money there and then...and according to what your age group is it's already there: you know exactly what you're going to get and within 2 weeks you've got the money. And that's what Bob and I then had a bloody good time, with the government money!'*(Dora, fg1)
3. *'So you got a lump sum from the government, did you?'*(Amanda, fg1)  
*'Oh yes, it's everybody's entitlement'* (Dora, fg1)  
*'So I can get one for my mother can I?'* (Amanda , fg1, querying a retrospective claim).
4. *'We had to go for medicals, which I thought was absolutely disgusting.. to Nottingham.'*(Grace, fg3)  
*'My mum had medicals actually in the hospital.'*(Janet, fg3)  
*'...to be seen by a doctor for the serious Industrial Injuries benefit, and I actually said to the doctor, 'cos my husband was struggling to walk, "I think this is absolutely disgusting, you've got his notes there, you've got his X rays, you've got his scans. If you could change the diagnosis I'd be delighted, but you've got a terminally ill man" and I was angry.'*(Grace, fg3)  
*'I was angry about that.'*(Janet, fg3)  
*'My husband used to say to me "Don't get angry, it's just one of those things" and I says "it's not just one of those things, it's not bloody fair!"'* (Grace, fg3)

Relatives reported that civil compensation claims required the patient's comprehensive employment record. In many cases the employing firms no longer existed and relatives described searching for the patients' former workmates in the hope that they could provide supporting information, 5.18.1. Most relatives reported that they had no prior experience of litigation and found the legal process time-consuming and worrying, 5.18.2. Relatives recalled the upsetting situation in that many of them, and the patients, had known that the patient often died before the compensation settlement was agreed. The ongoing responsibility of pursuing the claims was described as a further burden for grieving relatives: in two cases husbands had specifically insisted that their wives must continue the claims after their deaths. Some relatives revealed that the benefits and compensation actually received were less than many had been led to believe by accounts in the media, 5.18.3.



Relatives' opinions differed regarding the apparently common practice of doctors combining disclosure of the diagnosis with advice to contact a solicitor in order to claim compensation. Most relatives recollected that the emphasis on claiming compensation and benefits at the time of diagnosis was inappropriate and unwanted. In contrast, the relatives in one group stated that it was necessary to proceed quickly: they supported compensation information at the time of diagnosis because the patients deteriorated so quickly. However, the general view was that information about benefits and compensation should not be raised at the time of disclosing the diagnosis but shortly afterwards. The relatives' priority was the care of their loved one; even with hindsight, and accepting the advantages of making early claims, the benefits and claims procedures were reported as distracting, stressful and time-consuming.

#### **Box 5.18: Civil compensation claims**

1. *'...the solicitor did come ...Jimmy was that ill. And I'm writing down names, what boats he'd worked on, he knew it was the late '40's, early '50's...and my husband looked at me, on the Wednesday before he died... and he said "You better fight this case because you realise those bastards have killed me, and you make sure you don't let it go! ...if you don't know all the details you've got to be a detective, you've got a lot of work to do.'* (Pam, fg2)

2. *'I says to him "I actually feel like a gold digger, sat down here" you know.'* (Mary Talking about her conversation with her solicitor):  
*'I know my husband wanted the money for my security, because he wasn't going to be here and he wanted it for financial security for me and my family'* (Grace, fg3)

3. *'It's a fraction... if you were in your '70's you got peanuts. If you were in your '40's you got more, obviously.'* (Susan, fg2)  
*'In the paper it said you were liable to £37,000-£40,000, but when you actually got the thing, if your husband's older, it's next to nothing.'* (Pam,fg2)  
*'I think you had to be 36 years old to get that much money, which was very rare.'* (Susan, fg2)

4. *'I really was disgusted that there should be something like that at the beginning of the illness. All well and good after my mum had died,. But to do it right from the very beginning and then every time you went: "Have you got in touch with a solicitor?", at the end of the day I did lose my temper and said "I don't want to know".'* (Janet talking about being told to see a solicitor at the time of diagnosis)  
(HC) *'Any other points of view?'*  
*'I think it's because there's a time limit on it, isn't there? Is it about 3 years or something? So I think this is why they do it, isn't it?'* (Mary)  
*'I think it's a good idea to proceed with, although it's hard to take it all in, you've got a terminal diagnosis been given you, you don't know how long you've got together but I think you do need to press on with that because a lot of the questions only my husband could answer'* (Grace, fg3)

Relatives described the coronial investigation as a source of major upset. Many relatives revealed they had either partial or no understanding of the procedure before the death of their loved one. Unprepared relatives described their shock at discovering at the time of the death that a death certificate could not be issued, that a post mortem examination had to be performed and that an inquest would follow. In most cases the initial procedure involved a police officer attending the place of death in order to conduct a formal identification of the body. It was apparent that, although most of the cases had been in areas of high incidence of mesothelioma, not all the police officers understood the difference between sudden unexpected or suspicious death and the situation in mesothelioma, in which death was expected, but unnatural, as a result of asbestos exposure. Amanda (fg1) recalled that when her father died, the police attended at the same time as the on-call GP. The police would not let the family be in the same room as the dead father and spent several hours questioning the family about his occupational history and their actions when he died; this caused them much distress. In other cases the situation was understood and approached with tact and sensitivity, particularly if a coroner's officer was involved, although they were not always available, Box 5.19.

One family was given the choice by the coroner whether or not to proceed with an investigation. They decided against this because the company responsible had folded and the bereaved wife '*could not bear the idea of further invasion of his body*'. This caused much discussion in the group about the lack of consistency of coroners' services, 5.19.2. The post mortem caused distress to all but one of the participants, regardless of whether or not they had been prepared for it. The exception was a wife who had requested a copy of her husband's post mortem report<sup>70</sup>. Some of the other participants in her group found this shocking and none of them had known that they could have requested a report. However this wife explained it had helped her to know that her husband had coped with a tumour weighing 7lbs in his chest and she expressed her admiration for his stoicism.

Two relatives recalled that the interim death certificate, issued by the coroner after the post mortem but before cause of death had been established by an inquest, was not recognised by bank and building society staff. The inquest was

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<sup>70</sup> She subsequently sent me a copy of the report

recalled as yet another major source of distress, and often held months after the death. Most carers reported that they had not been aware of the procedure, received inadequate information about it and found it threatening and distressing. One participant revealed that she was still waiting for the inquest of her mother's death twelve months later. Although relatives reported that in general they found the inquest helpful in terms of a public acknowledgement of the reason for the deaths, and useful in supporting a claim for civil compensation, none regarded it as giving them any personal support.

#### **Box 5.19: The coronial investigation**

1. *'I was told to go the next day for the death certificate. I rang up and asked when I could come for it and she said "Oh there'll have to be a post mortem". I said "Why? You know what he's died of, why... a post mortem?" so she says "and there's also to be an inquest". So I says "Oh, nobody bothered to tell me this yesterday, or any of my family!" I said "I don't want him to have a post mortem, he's gone through enough" It was a shock, a terrible shock'* (Edna, fg4)
2. *'...she had to decide if she was going to arrange the funeral or going to claim because then she'd have to have a PM. She'd to sign a letter saying she'd relinquish any right to a subsequent claim – wouldn't release the certificate until the coroner had the letter.'* (Moira)
3. *'I mean I just got this date for the inquest and I got a court summons, I'd been summonsed to court. It's not a very nice letter.'* (Grace)  
*'How does that make you feel?'* (HC)  
*'As though I've done something wrong.'* (Mary)  
*'Well yes 'cos it's not in our Coroner's court, it's in with the Magistrate's court, so you're sat there with people that have been doing wrong...'* (Grace)  
*'You are summonsed on 28th May... I'm summonsed, I've never been court summonsed'* (Mary, fg3)
4. *'Because they had to retest her lungs, her lungs had to go to Cardiff.'* (Janet explaining the reason for the delay in holding the inquest while histology was clarified )

#### **'No closure' – issues in bereavement**

*'It just goes on and on and on.'* (Amanda, (fg1)

Many of the participants reported that medico-legal processes continued for many months after the death of the patient. The inquest was still awaited by one relative, already 13 months bereaved, and others were still involved in compensation claims. Relatives told of delays in the legal process as, it seemed

to them, insurance companies tried to manoeuvre out of their financial responsibilities.

Two relatives admitted that they had still not been to collect their husband's ashes from the funeral director, in both cases several months after the death; it seemed that this was yet another task and almost too much for them. In one case the patient had left a map and instructions for his family to travel abroad after his death to visit a place that had been dear to him. His relatives viewed this with some mixed feelings, partly because of the expense but also because of the sentiment, nevertheless the family members were planning to carry out the instructions, 5.20.3.

As one widow said *'there's no closure'* – confirming her awareness of the impact on grieving caused by the ongoing legal actions, 5.20.5. Another relative described repeatedly getting upset on hearing of more local people diagnosed with asbestos-related diseases related to working in the shipyard where his father had worked.<sup>71</sup> Many relatives revealed continuing anger, in two cases wives reported that the experience had changed them and made them more assertive, 5.20.1. One participant had already joined a campaign group as her mother's experience had angered her so much that she wanted to help other *'asbestos victims'* and another had written a full account of her husband's illness in order to support his compensation claim which was a test case against a public service organisation, 5.20.4. On the other hand, one participant described that she found the new roles and responsibilities of a life on her own almost overwhelming. It was obvious that for many participants the groups allowed them to ventilate feelings that had been suppressed to a large extent, 5.20.6. It was also the first time that many had actually met another person who had experience of mesothelioma and who therefore understood the illness and its consequences. Perhaps as a result of the relief at being able to unload and finding others who shared their experience, all the groups bonded and there was little disagreement – confidences were exchanged as freely as tissues!<sup>72</sup>

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<sup>71</sup> She sent me a copy of her report and asked me to use it in any way to campaign for better treatment for mesothelioma patients. She has subsequently joined a campaigning organisation.

<sup>72</sup> At least 3 of the participants remain in touch and 2 have subsequently become active in support groups and campaigning for asbestos victims.

### Box 5.20: No closure

1. *'I feel very angry and very bitter still...I've had to learn to be a bit more assertive'* (Grace)  
*'I'm the same really, I'm very angry, but I've got stronger with it, with everyday life I won't stand back now, I'll put myself forward more than what I used to do before.'* (Janet)  
*'I'm angry... they'd known about it for so long and hadn't done anything about it.'* (Mary)
2. *'I haven't collected the ashes, I told you.'* (Dora, fg1)  
*'I haven't done that, my ashes are still at the funeral parlour.'* (Amanda, fg1)
3. *'I've got to go to Florence, 'cause he'd left a map for me to go...He left a map for me to go to a place in Florence in Italy. Could have been Coniston, it'll cost me a fortune!'* (Alan, fg1)
4. *'I've found out that in 2001 people suspected of having mesothelioma sufferers should get the benefits and not have a medical but in spite of that, in my mother's case, they would not allow the benefits until the biopsy proved it...and that's the injustice...I'm angry and I'm going to fight it.'* (Joy, fg6, who had become a member of an organisation fighting for justice for asbestos victims)
5. *'...it's ongoing, so no it's not sorted.'* (Jean)  
*'Yes, there's no closure' (laughing)...No closure, no, not at all, there isn't...'* (Jean, fg5)
6. However Jean, and others, apparently found the focus group experience helpful: *'I think actually coming here today is helpful to me, because I'm telling you things that I have told no one else, regarding the hospital and the treatment and things like that.'* (Jean, fg5)

## Summary

In this study almost half the families had some prior knowledge of asbestos-related disease although they may not have consciously related this risk to their own situation. The diagnosis was imparted to virtually all patients and their relatives with confirmation of a fatal outcome, no hope of curative treatment and, according to the focus groups, little attention to supportive or palliative care<sup>73</sup>. Relatives had little chance of denying or ignoring the fact that patients were dying due to constant reminders in the form of deteriorating health, disease burden and medico-legal procedures.

Although the diagnosis was often disclosed against a background awareness of asbestos-related disease, sometimes specifically mesothelioma, it almost always had a shocking impact on relatives. This contrasts with the stoical

<sup>73</sup> As also confirmed by the medical records survey, Chapter 3.

reaction in patients as described in the interviews in Chapter 4. The impact was worsened if healthcare staff were perceived to undervalue the importance of the relatives and failed to involve them in matters concerning the care of the patients. Relatives found lack of knowledge of mesothelioma in doctors inexcusable and are distressed by perceived 'medical nihilism'. The relative rarity of mesothelioma, poor prognosis, and lack of effective treatments, increased relatives' feelings of isolation and neglect and added to the devastating impact of the diagnosis. Most relatives felt that combining advice to pursue benefits and compensation claims with disclosure of diagnosis was inappropriate and distressing, discussed further in section 5.4. Inadequate communication skills and, in particular, lack of training in breaking bad news, appear to be evident in these reports.

As in other cancers, relatives have different information needs to patients. In mesothelioma, when time is short<sup>74</sup> and the disease is incurable, the relatives take a particularly active role in obtaining and handling information and were most critical of doctors for lack of knowledge and/or the willingness to discuss the situation with them. In contrast to the patients, the carers, almost all female, were actively searching for information and assistance and felt they had a right to be fully informed. When frustrated by inadequate information from healthcare professionals, relatives looked outside the medical profession for information, sometimes finding inaccurate unhelpful websites.

There appeared to be a lack of appreciation of the relatives' needs and no service that signposts them to appropriate resources. In addition there appeared to be confusion about relatives' right to information; sometimes this was complicated by concerns around confidentiality and at other times hindered by patients who censored the information available to their relatives.

There is a considerable physical burden of care for relatives coping at home, in some cases exacerbated because patients reject outside help. The dramatic and unpredictable nature of the disease and invasive interventions add to anxiety. Decisions around calling for help and medication issues are usually shouldered by the carer rather than the patient. Traumatic experiences of severe distress and uncontrolled symptoms in the dying phase create yet

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<sup>74</sup> Confirmed in the medical notes review, chapter 3.

more emotional pain for bereaved relatives and add to public (and professional?) expectations of mesothelioma causing a terrible death.

There is also a considerable emotional burden on carers who support rapidly deteriorating patients, often in comparative isolation. Part of the strain relates to the tension engendered by trying to carry on as normal in the face of impending death. Family carers frequently have other carer responsibilities and may be in the 'sandwich generation'. There is a considerable impact on carers' own health – physical and emotional strains may lead to inappropriate coping strategies, anxiety and depression, sometimes adding to their health risks, for example resuming smoking or excessive alcohol.

The burden of investigations and treatments affects relatives as well as patients. The traumatic investigations undergone by patients causes great distress to relatives and this does not appear to be taken into consideration by the healthcare system. System failures add to the burden on relatives: in the face of terminal illness, the responsibility for dealing with delays and inefficiencies is shouldered by relatives.

The lack of defined best practice and the lack of a treatment plan in mesothelioma add to uncertainty and feelings of helplessness experienced by relatives. Lack of medical expertise in mesothelioma, even in areas with a relatively high incidence, adds to relatives' anxiety and loss of confidence in doctors. Relationships with doctors and nurses make a major impact on the quality of the experience for relatives.

Dissatisfaction with the healthcare system resulted in three potential formal complaints: one because a patient was told the diagnosis alone when arrangements had been made for his wife to be present; another because a patient experienced severe pain during a procedure that appeared to have been conducted without adequate care or consideration; and the third related to unhelpful NHS Direct procedures when a patient was dying. These appear to be valid grievances but in all cases may have been avoided by a more patient-centred approach which took relatives into consideration.

None of the relatives had been used to making either state benefit or civil compensation claims previously. Relatives, who assume major responsibility for these matters need expert assistance in obtaining their entitlements but there is no system for this. These relatives found claiming state benefits somewhat distasteful and demeaning. Civil compensation is also complex, involves appointing a solicitor, and causes relatives a lot of work and anxiety, it often continues into bereavement.

Relatives are outraged that their loved ones have died an unnatural and potentially avoidable death – many consider it to be mass murder and, as such, a public disaster. The responsibility for dealing with medicolegal processes is usually borne mainly by relatives and is disruptive, stressful and time-consuming. Lack of public understanding of mesothelioma and also the coronial investigation may stigmatise mesothelioma and exacerbate social exclusion of relatives. Relatives all found the coronial investigation distressing, many only found out about it after the patient had died. The problems related to the interim death certificate that upset two families highlight the lack of public and professional understanding of the legal situation. Coronial investigations and compensation claims interfere with grieving and adjustment. Negative emotions and unresolved grief may persist for a long time after the death. The above factors may result in intensified and complicated grief and bereavement (discussed further in Chapter 7). These accounts revealed a lack of support services for bereaved carers of patients with mesothelioma.



# Chapter 6: Interviews with healthcare professionals

## 6.1 Introduction

This chapter reports the findings of semi-structured interviews with 10 healthcare professionals who were selected as having experience in the management of patients with mesothelioma. They were asked for their views concerning the disease burden, disease trajectory, and service provision for patients with mesothelioma. The purposive opportunistic sample was designed to give a range of perspectives from the main medical and nursing specialities involved in mesothelioma across the three locations. The participants were: a GP, Macmillan nurse, lung cancer lead nurse, lung cancer clinical nurse specialist, respiratory ward sister, respiratory physician, thoracic surgeon, clinical oncologist, palliative medicine consultant and the Mesothelioma Information Service nurse<sup>75</sup>, (referred to as the helpline nurse in the text). This sample was not intended to provide comparative data across the 3 sites but, where important differences were identified, they have been reported.

An interview guide<sup>76</sup> was used to ensure coverage of the following areas: the local history of mesothelioma; workload due to mesothelioma; comparison with lung cancer; the clinical management of mesothelioma; their role in explaining diagnosis; financial matters and medico-legal procedures; involvement with patients' family carers; and ideas about best practice. The findings are reported under ten subheadings that relate to major themes that emerged from the data. Quotes illustrating the ten major sections are placed in boxes at the end of each section, for example: 6.1.3 represents Box 6.1, quote 3.

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<sup>75</sup> See section 6 for a description of this service

<sup>76</sup> See Appendix 11

## 6.2. Mesothelioma in local context

*'Not your typical lung cancer patients.'* Respiratory ward sister

### *Local situations*

There was universal knowledge of the epidemiology of mesothelioma and the local contexts: all the professionals who were interviewed recognised that they were practising in areas of high incidence; all acknowledged the specific local history of asbestos-related industries; all agreed that the incidence of mesothelioma was still rising and that asbestos was the cause of mesothelioma although a history of asbestos exposure was not always obtained. One doctor expressed his theory regarding a neighbouring area with apparently similar industries that had an unexplained lower incidence of mesothelioma: he suggested that the later timing of exposure of the neighbouring workforce to blue asbestos may have accounted for the difference. There was recognition that patients often suffered from anxiety due to prior knowledge of the disease and its dire outcome, either from workmates or local media reports, and that this increased anxiety, particularly when awaiting diagnosis, 6.1.1- 6.1.5.

### *Workload*

Most of the healthcare professionals were involved in respiratory specialities, except for the GP and the Macmillan nurse; only the helpline nurse worked solely in the field of mesothelioma. In the three high incidence areas included in the study, professionals reported differing workloads due to mesothelioma depending on variations in local incidence and the size and type of population they served. The GP recalled that his practice saw one or two patients each year with mesothelioma<sup>77</sup>; the respiratory physician from a district general hospital saw 4 to 6 new cases a year; whereas the thoracic surgeon and his team working in a regional cancer unit dealt with two or three cases each week (not all of which were new cases). The Macmillan nurse reported caring for up to 10 patients with mesothelioma per year; she revealed that some patients were referred very late in their illness and in those cases her involvement was brief, although often intense. The respiratory ward sister recalled that fewer patients with mesothelioma were now admitted to her ward since changes in admissions procedures due to performance measures introduced in the NHS

<sup>77</sup> This concurs with data from the medical records review, Chapter 3, no GP saw more than 2 patients with mesothelioma per year in these high-incidence areas

Plan<sup>78</sup> (Department of Health, 2000) 6.1.4, 6.1.5. The helpline nurse reported over 1000 calls per year from patients and carers across the UK during the 43 months that the helpline was available<sup>79</sup>.

### *Comparison with lung cancer*

Healthcare professionals held differing opinions about the previous health of the patients with mesothelioma compared with patients with lung cancer. Most expressed the opinion that patients with mesothelioma were less likely to be smokers, generally fitter than lung cancer patients and often involved in physical activities and hobbies; in contrast, two respondents, the GP and the oncologist, reported their view that there was little difference between these groups of patients. The GP reported his view that mesothelioma is almost unique amongst malignancies in that no effective treatment was available. There was unanimous belief that patients with mesothelioma suffered from more severe symptoms, particularly complex refractory pain and recurrent pleural effusions, than patients with lung cancer. This view is supported by Nowak *et al's* (2004) study mentioned earlier, p20, and also by an Australian study investigating the needs of patients with mesothelioma, their family carers and healthcare professionals in New South Wales (Hawley *et al*, 2004). The psychosocial impact and burden of mesothelioma on patients and their relatives were reported by all the professionals, and recalled by several interviewees as being greater than that related to lung cancer. This was understood to be due to issues of causation, blame, complicated financial and medicolegal issues and the inevitably fatal outcome, 6.1.6-6.1.8. These views are supported by a study in lung cancer in which none of the 107 consultants surveyed identified depression and only 23.5% identified anxiety as 'a main disease-related problem' (Krishnasamy and Wilkie, 1999:64)

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78 Discussed in Section 6.11, Service provision issues: secondary care.

79 The Mesothelioma Information Service telephone helpline was funded by the charity, Macmillan Cancer Relief, from 1.7.1999 until 1.12.2002 at which point the helpline nurse retired. Macmillan funding has subsequently been directed to the support of a National Mesothelioma Resource Centre in Leicester which offers a helpline and a website for patients, carers and professionals as Mesothelioma UK.: [www.mesothelioma.uk.com](http://www.mesothelioma.uk.com)

### Box 6.1: Mesothelioma in context

1. *'...we've had some quite young patients die...I've had a builder and I asked him "How do you think you got mesothelioma?" and he said "Well in the '60s and '70s we used to have games with each other and cut the asbestos boards and see who could create as much dust as possible – we never wore masks or anything...I just knew it was going to happen"'* Lung cancer nurse specialist
2. *'some people have "Well I worked with it, I knew I was going to get it" Others are very angry and frightened seeing other people die of it'.* Lung cancer nurse specialist
3. *'... most of the people who worked in the shipyard have been in contact with asbestos at some stage.They can number the people in their apprentice school that have died of it' GP*
4. *'I would see about one [new patient] every two to three months. ...they used to make the [railway] carriages and the locomotives, there was a large amount of blue asbestos then...also the power station, installing boiler work and pipe work' Respiratory physician*
5. *'...a lot of them will have known workers who've had similar problems and so they have preconceptions of the disease, which tends to be quite distressing...we do deal with at least 3 or 4 cases a week...and of course we're at the crest of the wave in terms of incidence so I would expect that thoracic surgeons are going to be busier for the next 5 years.'* Thoracic surgeon
6. *'Not your typical lung cancer patients. Don't tend to be smokers... not middle class, but upper working class...mesothelioma... tended to be non-smokers.'* Respiratory ward sister
4. *'...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
5. *'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 than with the average lung cancer because it's a pleuritic disease rather than a lung disease really.'* Palliative medicine consultant
6. *'pain seems to be an issue at an earlier stage, and far more difficult to control.'* GP
7. *'...lung cancer patients on the whole were in a fairly poor physical state of health because they'd got ongoing bronchitis, emphysema...whereas the mesothelioma patients on the whole were extremely fit, inordinately fit...There was a lot of anger about it, a lot of feeling of injustice, I think, that affected their mental...the way they coped with it...I think the age had a lot to do with it...a lot were early 60's, looking forward to retirement...the biggest majority were actually non-smokers...an awful lot had never smoked, so the last thing they expected was lung cancer of any kind...a lot are very diet and health-conscious, so they were quite different from the lung cancer group, who were the exact opposite really! ...and a lot have very active sporting hobbies.'* Helpline nurse
8. *'...the biggest thing that's obviously different ...the first symptoms tend to be acute...persistent effusions, which of course lung cancer patients can get...but they do seem to go through the mill a lot...having to go away for pleurodesis, a longer time of uncertainty...and the big thing is the financial side...which causes a lot of stress.'* Macmillan nurse

### 6.3. Investigations and interventions

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

There appeared to be particular difficulties inherent in caring for patients with mesothelioma. Healthcare professionals reported their perceptions of problems occurring throughout the illness and affecting every discipline. Many recalled the extensive investigations and frequent delays in reaching a histologically confirmed diagnosis, as reported previously (Yates *et al*, 1997; BTS, 2001; Hawley *et al*, 2004), and that this was distressing for patients, relatives and clinicians. Professionals reported the investigations as painful or 'harrowing' for patients due to a combination of invasive procedures, long periods of uncertainty and anxiety, 6.2.1, 6.2.2. However, the respiratory ward sister remarked that patients with mesothelioma appeared to be very accepting of seemingly painful procedures, 6.2.3. Echoing previous reports, (BTS, 2001, Hawley *et al*, 2004), interviewees reported that the diagnosis remained unconfirmed for some patients in spite of extensive investigations and/or a strong suspicion of mesothelioma against a history of asbestos exposure, 6.2.4.

The thoracic surgeon described accurate staging as crucial to determine whether radical surgery was appropriate. He reported problems relating to both the inaccuracy of available investigations, (thoracoscopy and CT and MRI scanning), and the inadequacies, as he saw them, of current staging criteria. He explained his concern that an underassessment may result in patient receiving inappropriate radical surgery, with consequent high morbidity and poor outcome, due to their having advanced rather than early disease, 6.2.5, 6.2.6. His views are supported by previous studies (Rusch and Venkatraman, 1996, Edwards *et al*, 2000).

Prophylactic radiotherapy, to prevent tumour tracking along chest wall ports, was seen as essential by several interviewees, as recommended by previous authors (Boutin *et al*, 1995; BTS, 2001). Problems were reported in complying with the BTS recommendation (2001) that radiotherapy should be given within 4 weeks of the invasive procedure: two healthcare professionals reported delays due to waiting lists but two others reported faster access to treatment since

MDTs had been introduced.<sup>80</sup> Another radiotherapy access issue was related to distance; only Leeds, a regional cancer centre, provided radiotherapy locally; patients in Barrow and Doncaster had to travel up to 70 miles for radiotherapy.

The relative rarity of mesothelioma and consequent lack of knowledge of the disease amongst doctors, juniors in particular, was highlighted by a Macmillan nurse. She reflected that patients with pleural effusions were disadvantaged when mesothelioma was not suspected as a diagnosis or incorrectly thought to be a benign condition.

### **Box 6.2: Investigations and interventions**

1. *... the other thing that's hard with mesothelioma patients is the diagnosis is so difficult to get, so they've agonised, usually for weeks, sometimes months... So they've had all this agony before they eventually are told the diagnosis.* Respiratory ward sister

2. *'.. the difficulties of diagnosis can be harrowing for the patient.'* Thoracic surgeon

3. *'They're very accepting, when they... have it aspirated. I think they are painful procedures... it looks uncomfortable, it looks painful. But mesothelioma patients do seem very acceptable of it... It's a big chunk of their time... they sit there with the drain in and they have the pleurodesis, and that in itself can take up to a week, then if it fails and they're back in again... They're also starting... sending patients home with drains from surgery, but I think they bring complications as well.'* Respiratory ward sister

*'...they get sent for pleural aspiration, cytology, and if they suspect mesothelioma they get a CT scan and either a needle biopsy guided by the CT or for a VATs biopsy next... Sometimes ...all the investigations are non-contributory and one is forced just to wait for a passage of time to identify whether it's a malignant mesothelioma or a benign pleural reaction.'* Respiratory physician

*'...we know this is a depressing disease... the majority of patients we see are not suitable for any potentially curative surgery... It's all palliative, most of the patients we see are referred either for diagnosis because the chest physicians haven't been able to get a diagnosis [or] do a surgical procedure... so we are quite involved ...'* Thoracic surgeon

4. *'I don't think this is a disease that you can stage like lung cancer, I think this is a diffuse disease that effectively are all T4... you could even say they are all M1 because I don't think current classifications are really suitable... I think it's important to stage them with mediastinoscopy... But really these are all extensive stage disease... but you do get occasional patients... where you've just got very early studding of the parietal pleura, and I think they would do well with pleuropneumonectomy and pleurectomy, but you don't get many cases like that.'* Thoracic surgeon referring to TNM staging classification

5. *'...and I think it's education [that is needed.]... educating the junior doctors that if someone's admitted with a pleural effusion... make sure they're referred back to the chest team and not just discharged and left 'til the next time which was happening with a lot of them.'* Macmillan nurse

<sup>80</sup> See later description of multidisciplinary teams in Section 5: Service provision, p242

## 6.4. Professionals' views of treatments and trials

Most of the interviewees emphasised the lack of effective treatments, and consequently that all interventions were essentially palliative. They reported that this was a hard message to convey to patients and their relatives, see Section 6.6, Talking to patients. The lack of clear guidance on best practice, such as an evidence-based clinical pathway, was seen by some as disadvantaging patients with mesothelioma but, on the other hand, several participants stressed that individualised care is essential in this situation, 6.3.1, 6.3.2, 6.3.8, 6.3.9. The helpline nurse contrasted this with lung cancer management where she felt that a standardised treatment plan was more appropriate, 6.3.2.

Two doctors revealed their involvement in novel treatments: the consultant in palliative medicine described how he was involved in exploring the use of ketamine, an anaesthetic agent used 'off label'<sup>81</sup> with encouraging results<sup>82</sup> (described later in Section 6.5, Palliation of symptoms), and the thoracic surgeon reported that he was participating in a trial of intra-pleural photodynamic therapy, in cooperation with other specialist centres, 6.3.3, (Baas, 2006). The surgeon reported that dismal results from radical surgery earlier in his career dissuaded him from surgery in mesothelioma but that he had now restarted in the light of recent published studies.

Chemotherapy was recalled as another difficult area in the light of disappointing results of trials and the opportunity costs for patients, even enthusiasts for chemotherapy expressed an awareness of the treatment burden for patients and the limited benefits. The helpline nurse went even further: she expressed scepticism about the benefits of chemotherapy and doubted that a successful treatment would be discovered until mesothelioma was in decline, 6.3.4, 6.3.5. None of the participants advocated chemotherapy outside a clinical trial, 6.3.6. It was reported that some patients subsequently regretted having chemotherapy because it made them ill in the short time they had left and the Macmillan nurse

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<sup>81</sup> 'Off label' is commonly used to describe the use of medication outside licensed indications

<sup>82</sup> Ketamine is licensed for use as an anaesthetic, it is now becoming widely accepted in palliative medicine and specialist pain services as a useful analgesic, particularly in addition to conventional agents such as opioids, in severe pain.

implied that, in spite of any explanations that may have been given, some patients had not fully understood the risks and limited benefits of chemotherapy, 6.3.7. Ethical issues involved in entering patients into chemotherapy trials were raised by four interviewees: these anxieties centred around the delicate balance between giving accurate information about very limited improvements in survival times and dashing all hope for patients. These four professionals reported their expectation that chemotherapy may harm rather than help or, at best, offer minimal benefit to patients, 6.3.8, 6.3.9, 6.3.10. There was criticism of the media, including unregulated websites: professionals reported concerns about publicity surrounding new drugs for mesothelioma without full explanation of the results of relevant trials; this was reported as appearing to confuse and raise false hopes for patients and their families, 6.3.11.

The professionals' views about chemotherapy in mesothelioma, 6.3.3-6.3.10, suggest an interesting divide: although almost all interviewees regarded clinical trials as necessary in order to search for effective treatments, there was a difference between, on the one hand, the secondary care doctors: the respiratory physician, oncologist and thoracic surgeon; and on the other hand, the primary and palliative care professionals: the GP, palliative medicine consultant, and Macmillan nurse. The secondary care doctors appeared to encourage patients to participate in trials. This was perhaps from a strategic or utilitarian perspective as the only way in which progress was to be made and in the belief that chemotherapy might confer some limited benefit to the individual patient. Contrastingly, primary care and palliative care professionals tended to be much more cautious about promoting chemotherapy trials and appeared to prioritise the potentially negative effects of the treatment in terms of impact on the patient's life with regard to treatment burden, opportunity costs and potential harm. This difference could be seen as reflecting the different levels of relationship between the patient and the professional, although these comments must be viewed in the context of this small sample. Whereas patients are seen at longer intervals and for specific advice and interventions by secondary care professionals, the primary care and palliative care professionals (in general) have more contacts with the patients and usually know their family and social situations and may have longstanding relationships. The greater intimacy of these relationships may lead to an approach that tends to be more patient-



centred. However, in primary care, it is unlikely that the practitioner will always be aware of the latest results from oncological clinical trials.

The respiratory ward sister and the lung cancer nurse specialist also seemed to fit with the patient-centred approach. This corresponds to their more in-depth knowledge of the patient and their family as a result of daily contact during hospital admissions or repeated detailed discussions of the disease and treatments, in comparison with the relatively brief contact with most secondary care doctors. It also relates to nurses' professional training in which 'getting to know' patients and their families is central to nurses' identity, although this cannot be seen as exclusively related to nursing. GPs, palliative medicine physicians, psychiatrists and also many hospital doctors would regard the doctor/patient relationship as in itself therapeutic and dependent on an understanding of the patient and their family (Kleinman, 1988:222; Cassell, 2004:144-7, Randall and Downie, 2006:176-9). Another stereotypical view of the different behaviours may relate to gender: all the nurses were female, all but one of the doctors were male. A contrasting view, considering a brief involvement with a patient at the end of their life, might suggest that a professional, supportive, albeit superficial, relationship may be the best that can be achieved.

### Box 6.3: Professionals' views of treatment and trials

1. *'There's no clear cut protocol or pathway that these patients should follow, and I think It would probably be nice to standardise.'* Thoracic surgeon
2. *'I think they're very individual and...that is probably the key to their care. I found with lung cancer you could work along quite firm lines, you saw one patient and... providing they were the same type of lung cancer, the care didn't vary a lot, but with mesothelioma, no, it's a much more individual disease...the person needs to be treated as an individual.'* Helpline nurse
3. *'Yes, I think there's a lot of problems with trials...I'm interested in photodynamic Therapy for mesothelioma...We have pre-operative chemo, intra-pleural pneumonectomy with photodynamic therapy during the operation, followed by radiotherapy. Which is a lot for the patient to undertake...You do need a laser...the equipment's fairly expensive but we got it in Leeds...but that's not even been really thought about in these trials.'* Thoracic surgeon
4. *'Yes we support the clinical trials, we're enthusiastic to recruit our patients to trials and that does often mean that we are particularly keen to get a histological diagnosis... so it does impact to some degree upon issues like biopsies and so forth.... I don't have problems so long as patients are properly recruited and give proper informed consent'* Respiratory physician
5. *'I think they're essential because we've got to try I suppose. My feeling is...by the time they get some success mesothelioma is going to be on the decline anyway...I've spoken to people who have had dramatic benefit from chemotherapy...others have just gone downhill...others that have had no treatment and they're going on nicely, 2 years on...My interest in mesothelioma predates chemotherapy for mesothelioma, and I had patients then who were living 2 or 3 years, in fact sometimes I think they lived longer.'* Helpline nurse
6. *'If they have chemotherapy it must only be as part of a trial.'* Oncologist
7. *'...sometimes I get patients saying "If I knew I was going to be this ill I may not have chosen to have active treatment, because I wanted to feel well in the short time I had to live"'* Lung cancer clinical nurse specialist.
8. *'Again it's the individual's interest against the greater good, isn't it? Basically it's pure academic research. I mean if the academics turn out a new type of chemotherapy which theoretically should make a difference, then that's different, you'd go for it. But if you've got a reasonable body of evidence which shows that really it's not going to tangibly improve your quality of life, then I don't think you should do it.'* GP
9. *'These people have been through a lot already, their life expectancy isn't long, and you've got to be careful about what you subject them to. So I am rather negative about the whole area'* Palliative medicine consultant
10. *'I think it's very difficult to take hope away from patients, and often my perception is that they're offered that lifeline and they grab it, and it's a very brave person who says "Well no I don't really want to try that..." They usually opt to have treatment and often relatives can push them.'* Lung cancer clinical nurse specialist
11. *'the [local paper] putting in that there was this new wonder drug that would give them an extra 12 months quality life without actually looking critically at the article...'* Macmillan nurse

## 6.5. Palliation of symptoms

The severe symptom burden for patients and the challenge of achieving good symptom control were referred to by all the professionals, in accord with previous reports (Hawley *et al*, 2004; Nowak *et al*, 2004; Mercadante *et al*, 2000; Jackson *et al*, 1999; Ahmedzai and Clayson, 2006). In line with recent NICE guidance on palliative and supportive care, (NICE, 2004), two professionals emphasised that palliative care should be provided to patients with mesothelioma from the point of diagnosis, 6.4.1. In contrast, two others, including the consultant in palliative medicine, seemed to regard it as relevant when active treatments were no longer appropriate. Several participants, in both hospital and community settings, stressed the need for specialist palliative care knowledge in managing patients with mesothelioma due to the complex and multiple nature of their symptom, 6.4.2 – 6.4.10. Although palliation of symptoms in general was reported to be difficult, the major focus was on the relief of pain 6.4.1– 6.4.3. Most professionals recalled experiences of patients in whom pain had been very difficult, sometimes impossible, to control adequately. Four interviewees stressed the complex nature of refractory pain with multiple potential causes of the pain, sometimes worsened by chronicity and ‘wind up’<sup>83</sup> (Stannard and Booth, 1998:11) 6.4.5, 6.4.6, 6.4.9, 6.4.10. The desperation of professionals in this distressing situation was illustrated by the consultant in palliative medicine who declared he was prepared to ‘*try anything*’ to relieve pain in mesothelioma when conventional treatments had failed, 6.4.5. The consultant in palliative medicine who reported that he was actively investigating an ‘off label’ medication, ketamine, in response to the refractory nature of pain in some patients, emphasised the need to admit patients to a specialised unit such as a hospice in order to introduce this novel and complex treatment regime, 6.4.5. The need for a rapidly responsive service was emphasised by two professionals who referred to the erratic and often dramatic disease trajectory 6.4.4, (p282).

Breathlessness was seen as mainly due to pleural effusions. It was regarded as treatable with pleural aspiration followed by pleurodesis if it became a recurrent problem. Surprisingly, other causes of mesothelioma-related breathing difficulties, such as extensive rigid pleural thickening, lung encroachment by

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<sup>83</sup> ‘Wind up’ is a phenomenon in which peripheral nerve damage is accompanied by central sensitisation, reflecting plasticity at all levels of the nervous system

tumour, or pericardial involvement, were not specifically mentioned by any of the interviewees. Impressions of inefficiency in the management of recurrent pleural effusions were reported by two interviewees. The respiratory ward sister reported that talc pleurodesis performed as a procedure on the respiratory ward often failed and then patients required a further attempt in a thoracic surgery unit. The same nurse also referred to inappropriate use of nebulisers, 6.4.7, 6.4.8. The lung nurse recalled junior doctors failing to consider mesothelioma as a cause of pleural effusion, 6.4.7, 6.4.11. Delayed referrals and long distances for some patients to travel to thoracic surgery units were also seen as disadvantaging patients with mesothelioma, 6.4.3, 6.4.7. Non-pharmacological techniques to improve patients' control of their breathing have been shown to be effective (Bredin *et al*, 1999). However, this was not formally included in any of the professionals' roles and was acknowledged as a significant omission by three nurses who knew the literature, 6.4.8.

Several reasons may explain the lack of attention to breathlessness due to causes other than effusions. Firstly, almost all patients with mesothelioma are short of breath and effusions are the most common factor and aspiration is an effective and immediate treatment; possibly less acutely breathless patients may be managed at home and therefore not brought to the attention of hospital staff. Secondly, there may be no useful *medical* intervention for breathlessness due to trapped lung or lung invasion (if the patient is not fit for surgery). Thirdly, although severe breathlessness is just as visible as severe pain, it is possible that there may lower expectation that it can be relieved. In contrast, in a national survey of patients, carers and healthcare professionals concerning lung cancer, breathlessness was seen as the most challenging aspect of disease management by GPs. This should be seen in the context of knowledge that pain is less common in lung cancer than in mesothelioma (Nowak *et al*, 2004; Krishnasamy and Wilkie, 1999:53).

Healthcare professionals reflected that some colleagues had inadequate knowledge of mesothelioma and suggested that this was due to the relative rarity of mesothelioma. A Macmillan nurse recalled junior doctors who appeared to have no understanding of mesothelioma and in one case had thought it was a complication of chronic lung disease related to smoking, 6.2.7. From her previous experience as a lung cancer nurse specialist, this respondent also

reflected that specialists outside the respiratory team were uncertain how best to manage patients with mesothelioma and so they readily referred them to the respiratory physicians. This contrasts with the low level of referrals to palliative medicine found in the medical records survey, Chapter 3, p119, and concurs with the healthcare professionals' reports that they did not experience any systematic involvement of the specialist palliative care team by the respiratory or oncology specialists, even when a full palliative care service was available. This reflects similar issues concerning low referral rates of all cancer patients, and specifically lung cancer patients, to palliative care services, in spite of the acknowledged benefits to patients (Hearn and Higginson, 1998; Krishnasamy and Wilkie, 1999; Muers *et al*, 1993; Hawley *et al*, 2004). Negative attitudes of other doctors to the relatively new speciality of palliative medicine may contribute to low referrals as well as lack of understanding of when and why to refer (Hanratty *et al*, 2006). There may also be issues around the doctor-patient relationship that inhibit referral to another specialist, particularly if several specialist teams are already involved, for example, respiratory medicine, oncology, radiotherapy and thoracic surgery (Smith *et al*, 1999; and Table 3.20, p118)

#### **Box 6.4: Palliative care**

1. *'So you're immediately into a palliative care situation, immediately you're saying "Well, OK, we can't cure it but let's see what we can do about the symptoms, you shouldn't have to suffer" and then you've got to try and deliver that.'* GP
2. *'... pain can sometimes be a real problem and we sometimes see really challenging situations, infiltration into the spinal cord and paraplegia and all sorts of other things can arise so they do have a lot of specific palliative needs...'* Respiratory physician
3. *'...in my experience, I think pain is the biggest, major symptom, and breathlessness is usually associated with pleural effusions... they're drained, and then patients can return to an adequate... we do talc pleurodesis on the ward, but to be honest they're often not that successful... usually they present back with them, and then they'll go for surgical pleurodesis...the main issue is the pain...'* Respiratory ward sister
4. *'...they often present with chronic pain problems, neuropathic pain, not well...The patients often have got so many different symptoms, pleural effusions, neuropathic pain, weight loss, general fatigue, malaise...Some deteriorate within weeks while they're having investigations, you've got to act very quickly.'* Lung cancer clinical nurse specialist
5. *'It was largely the mesothelioma patients that started my interest in ketamine, and I found that generally quite useful for the more chronic sort of wind up, complicated pains that were perhaps only partly opiate-sensitive... there would be a chronicity to it... you've got stromal constriction, you've got pleural involvement, you've possibly got invasion of ribs and intercostal structures... there might be four or five components to it. I guess that then became my main technique...using ketamine to an adjunct to all the other things...I'll try anything...'* Palliative medicine consultant
6. *'They tend to give MST and not look at the other types of pain...neuropathic pain...pain management is a problem at times.'* Macmillan nurse
7. *'I don't think they (effusions) are always managed effectively...I think people tend to do an aspiration and wait for the results to come back...meanwhile the fluid's building up again, sometimes they've had 2 or 3 aspirations already...'* Macmillan nurse
8. *'...patients are often put on a nebuliser, but they're not effective with mesothelioma...We don't as such do breathing control... when patients are feeling breathless we can massage their back and just try and slow things down a bit and relax them.'* Respiratory ward sister
9. *'...particularly when it comes to symptom control, underprescribing is a major problem...they need hospice contact and advice... from pain control specialists really....'* Thoracic surgeon
10. *'... district nurses are brilliant - they're very pressurised but... they don't do specialist palliative care...these patients have very unique and difficult problems, they're quite complex ...you might solve one problem and cause another with drugs... so you've really got to know how to use...a combination of drugs, you just can't go in upping morphine all the time, that's not going to get rid of the pain.'* Lung cancer nurse specialist
11. *...they don't realise it's a malignant disease... nurses, junior doctors... didn't understand [this lady] had cancer...they said... 'Yeah, it's to do with her COPD'* Macmillan nurse

## 6.6. Talking to patients

*'...it's the lack of explanation that most people...suffered from.'* Helpline nurse

### *Explaining diagnosis and treatments*

Two areas were reported as causing much concern with regard to communications with patients: firstly, disclosing the diagnosis, and secondly, explaining the limited treatment options. Doctors responsible for delivering the 'bad news' of a diagnosis of mesothelioma all acknowledged that they found this difficult. They explained that the difficulty centred on the hopelessness of the message: the fatal nature of the disease and the lack of effective treatments, 6.5.1. At the same time as the patients were told that they had mesothelioma, most doctors also informed them that it was an occupational lung disease entitling them to related Industrial Disease benefits and civil compensation (described in 6.8), 6.5.2. All the nurses who were interviewed saw interpretation and explanation of the information given to patients by doctors as a vital part of their role. Nurses recalled that, in many cases, they saw patients immediately after doctors had disclosed the diagnosis, and that they had more time to give further explanations of the disease and any treatment options. For example, nurses reported that they provided booklets about the illness, 6.5.2, 6.5.6. Doctors and nurses appeared to agree with this division of tasks, although two nurses recalled that they sometimes felt compromised because they felt they had less in-depth knowledge than the doctors, 6.5.2, 6.5.3. The role of the nurse as key informant and advocate for individual patients was emphasised by the lung cancer nurse specialist, respiratory ward sister and the helpline nurse, 6.5.3, 6.5.4.

Concerns about communicating the treatment options to patients and their families, particularly in the absence of clear treatment guidelines, were expressed by both doctors and nurses but some of the key issues perceived by each group were different. As described in the earlier section on treatments and trials, doctors reported dilemmas in trying to advise patients whether or not to accept palliative chemotherapy. Many were concerned about the opportunity costs for patients with a short time to live and the poor results of trials to date. In some cases this was against a background of support for clinical trials as the only way in which future patients might be helped. The oncologist and the

helpline nurse both expressed the belief that patients should be encouraged to participate in trials. However the nurse qualified her response by stressing that ultimately it should be the decision of a fully-informed patient. There was some criticism of doctors by nurses. This related to the selective or limited detail of information that doctors apparently gave to patients, particularly with regard to treatment options, which left the nurses in the potentially difficult position of trying to expand on the situation without seeming to contradict the doctors, 6.5.4, 6.5.5.

Two nurses reported that some patients were in shock or very ill at the time of diagnosis and could not absorb any more information, 6.5.3, 6.5.4. Three nurses expressed disquiet about the information that was given to patients by doctors concerning chemotherapy trials, 6.5.4, 6.5.5. The nurses' comments suggest that incomplete information was sometimes given, in other cases the patients did not understand the details and needed more time with senior doctors, 6.5.3, 6.5.4, 6.5.5. The nurses proposed differing explanations for inadequate information being provided: that oncologists may have a vested interest in recruitment to trials, or that other doctors who feel that trials have little to offer patients may be uncomfortable about raising the issue. In the absence of any offer of other treatment options, including palliative care, one nurse suggested that patients decide on the basis of '*willing to try anything*', 6.5.4. The helpline nurse's comments suggest that she perceived some doctors as having a paternalistic or possibly patronising approach to patients, 6.5.5. All the nurses interviewed appeared to accept assisting patients with decision-making around clinical trials as part of their advocacy role. Although great responsibility was placed on specialist nurses in following on from the doctor and giving further explanations and advice, it appeared that some nurses had criticisms of doctors' communication with the patient but were unable or unwilling to raise this with the doctors concerned, 6.5.4, 6.5.5. Comments by the GP and palliative medicine consultant, included in Box 6.3 on the section concerning treatments and trials, illustrate their awareness of the influence of doctors and relatives on patients' decisions about chemotherapy and the tendency of vulnerable patients to 'clutch at straws', 6.3.8, 6.3.9, 6.3.10.



## **Box 6.5: Talking to patients**

1. *'...often my responsibility is the breaking of the diagnosis for a condition for which there is generally no particularly effective treatment, and with the added complication that this is something that is caused by their work and so there's quite a lot of psychological activity...I will often see the patient with a relative and that can be quite interesting...the relative often has a lot of needs as well...They're generally encouraged to bring somebody along when they're getting the news, and we will also give them the opportunity if they haven't done that, to come back again with a relative... some patients won't want anyone else and we would obviously respect that.'* Respiratory physician

*'...we do involve the lung nurse, often at the first visit...the nurses are introduced early on in the process, and certainly at the time of diagnosis we would like to have one of the lung nurses present, that's very appropriate...The lung nurses have got a lot of the literature...some very good booklets about asbestos-related disease...it is obviously an important part of my job to say "Look, this is an occupational lung disease and this is the diagnosis and these are the important priorities" - the notification of the DSS, the pursuit of civil compensation as well.'* Respiratory physician

2. *I find that I like to be there when a patient is told a diagnosis, and you do find that once the medic's gone they have questions, it's a shock, isn't it? And I answer what I can, but obviously I can't go as deep as a medic.'* Respiratory ward sister

3. *'Sometimes we try and explain to patients that it's not really going to make a significant difference to their lives, we may be talking a few weeks for certain treatments, and that sometimes makes them take stock...They often are told that immunosuppression is a risk, that they could die, that they're going to lose their hair, it's going to make them feel ill, etc, and they are often not given an alternative, and if that wasn't offered, what would happen and what they would experience, and if they didn't have active treatment now, what would be available for them in the future, could they come back and decide to have treatment in 6 or 8 weeks time or 3 months?'*

HC: *So you are saying those alternatives are not spelt out?*

*'No, not in direct terms whatsoever. Only if a patient asks, or a family ask directly, is it spelt out and the same with their prognosis.'*

HC: *'It sounds as if there needs to be someone interpreting the situation for patients. Is that something you would agree with?'*

*'... the doctors try not talking jargon now, try and talk in simple terms...that concept is very difficult for the patients to understand, the greater picture of what's going to happen. They don't know what's ahead of them...or they may have seen some work friends die of mesothelioma, and so they take what's on offer... We should be doing follow-up phone calls, ringing them and saying "How are you? We're around if you need us" and try and see them again to explain what the doctors have said and give them their options afterwards...very much a big part of our role.'* Lung cancer nurse specialist

4. *' the doctors here tend to, kind of, mention it [ clinical trials] quickly, then carry on About something else because they know that, more often than not, it's not going to help, but I think they should all be given that choice...some patients, no matter how poorly, want to go down that route but they need guidance and support and information....'* Macmillan nurse

5. *'... it's the lack of explanation that most people that rang ...suffered from... they should be told exactly what's available and... the truth about clinical trials and the results of the trials... what is possible and what's not, and left to choose for themselves. The majority are very intelligent people, they're quite capable of making the decision if they are given the right information, but they are often not. So giving good information I think is vital, and giving written information that they can go home and take with them.'* Helpline nurse

## 6.7. The Mesothelioma Information Service

The helpline nurse<sup>84</sup> described how she had become aware, while working as a Macmillan nurse, of the unmet information needs of mesothelioma patients, 6.6.1. This had prompted her to obtain charitable funding from Macmillan Cancer Relief in order to set up the Mesothelioma Information Service<sup>85</sup> in 1998. This service provided a national telephone helpline for patients, carers and professionals. She told how this led her to produce an information booklet<sup>86</sup> and also to develop the Mesothelioma Nurses Network<sup>87</sup> that aimed to educate and support nurses working with patients with mesothelioma. The Information service was valued as an educational resource; the helpline nurse reported frequent calls from nurses as well as patients, family members, solicitors, social workers, 6.6.2.

The reasons for calls to the helpline reported by the helpline nurse reflected deficiencies that patients and carers perceived in the information given to them regarding basic details of the disease and the difficulties in establishing a diagnosis, 6.6.1. In some cases she reported a sense that patients and their families had lost confidence in their doctors due to poor communication resulting in little understanding of the disease, treatment options and symptom control services, 6.6.1. The dissimilar types of information requested by differing groups of callers were described by the helpline nurse: patients wanted her to advise on their prognosis, main carers wanted to know about treatment options and how patients were likely to die, whereas younger relatives were often asking for clarification of information obtained from the Internet as well as prognosis, 6.6.3-6.6.6. Carers' and other family members' queries also related to needing to know about managing the disease and some idea of time frame so that they could try to plan ahead. Some carers reportedly used the helpline when they had experienced difficulty in obtaining information from the patients' doctors.

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<sup>84</sup> Inevitably, confidentiality cannot be maintained here. Explicit written consent to include this section and quotes was obtained from the helpline nurse concerned.

<sup>85</sup> The Mesothelioma Information Service was originally run from Leeds, Yorkshire. It has now moved to the Macmillan-funded Mesothelioma National Resource Centre in Leicester and has been absorbed into the newer national charity, Mesothelioma UK, set up in 2004

<sup>86</sup> 10,000 copies were printed in 2003

<sup>87</sup> The Mesothelioma Nurses Network, set up by the helpline nurse, held regional and national educational meetings to inform nurses about clinical, financial and medico-legal aspects concerning mesothelioma.

The helpline nurse reported that she kept up-to-date concerning travel insurance in order to help patients take a final holiday with their families. The helpline was also a useful resource for professionals: nurses called the helpline to request information about mesothelioma both in the form of booklets but also clinical advice concerning symptom control and technical issues such as managing chest drains, 6.6.2. Solicitors and social workers also contacted the helpline, often to clarify details of the disease or treatments. The helpline also provided a focus for some relatives bereaved due to mesothelioma: some rang to speak to the nurse who they had got to know during the patient's illness, others needed to talk to someone who understood their experiences.

The calls to the helpline illustrate apparently major unmet needs with regard to the provision of information for patients and their family carers concerning this terminal illness as provided by statutory services. The calls also highlighted the differing information needs of patients and carers as also described in Chapter 5, Focus Groups with bereaved relatives.

**Box 6.6: The Mesothelioma Information Service: Quotes from the helpline nurse**

1. *'A huge number didn't even understand anything about the disease...They couldn't understand the delay in diagnosis, this came very clearly....why it takes so many investigations, so many X rays, so many biopsies, etc. So quite a few were quite disillusioned with the medical profession because they thought...they'd ring up to ask if they should get a 2nd opinion because they were dealing with somebody who was obviously incompetent, that couldn't make a diagnosis. And that was partly the lack of explanation about the disease....as to why all these things were happening, and describing to them the actual disease and how it worked, how it affected the outside of the lung...and it wasn't a big ball...that's how people imagine cancer, and that it didn't show on a straightforward X ray... Some were in great distress because they'd got somebody they loved in terrible pain and they weren't getting the services they needed... but that was not as common as the wanting to understand what was going to happen.'*
2. *'The biggest number of calls were from carers, the second biggest number... were from patients, and the third biggest number of calls were from relatives such as sons and daughters...the professional calls, most of those were from nurses wanting more information about mesothelioma, wanting booklets... things about pain control, symptom control...chest drains, which are quite a problem for some of the mesothelioma patients...other professionals as well – social workers, solicitor...we used to get quite a lot of bereavement calls'*
3. *The carers' questions were "How is he going to die?"... a common question. I think they'd tried asking the doctors and they'd been brushed off, and sometimes it was done very badly...they'd been: "We don't have to communicate with the carer" ...some of the carers felt that there should be a situation where the carers could speak to the consultants in a private capacity, because they were the ones having to cope...and finding it very difficult.'*
4. *'The patients were often far more straightforward than the carers and would ask "When am I going to die?" not necessarily how, they wanted to know when? How long had they got? And some had asked the doctors and been fobbed off with all kinds of rubbish really, sometimes quite awful things like "Oh you've got years" (laughing). It was just awful really... because I hadn't access to their medical records, I could only guess how it would be for them, and I tended to ask them a few questions about how they were, was their appetite good, was their weight stable, etc, their energy levels...and from that make some guess as to whether they'd got an aggressive form or whether they were going along quite nicely, and kind of give them a range of time...that was usually quite acceptable...because they'd had an explanation that it was quite different from person to person and that the cell type governed how long they might have, and it was just somebody talking to them about that really, not actually telling them how long they'd got, quite different to the question they were actually asking, which was "How long have I got?''*
5. *'Daughters and sons...they'd usually be on the Internet (laughing) because they tended to be younger...their questions were often about chemotherapy, treatments, should they go to America...their calls were slightly different...things like "I'd planned to get married in January, should I bring it forward?''*
6. *'...things like travel insurance – a virtual impossibility to get at a reasonable cost, and a lot of these people, because they knew they were dying and their time was limited, wanted to take a holiday and they'd been quoted phenomenal fees. So I actually produced a sort of insurance thing, I'm still getting calls about travel insurance. £4000 being quoted for a fortnight's holiday in Europe! It's just a way of saying "We don't want to insure you"*

## **6.8. Explaining state benefits and civil compensation**

In addition to information about the disease, interviewees recalled that patients and their relatives also needed accurate information regarding benefits and compensation. However there was disagreement about when was the best time to inform patients that mesothelioma, as a prescribed industrial disease, entitles patients with industrial asbestos exposure to state benefits and civil compensation. Three nurses, the Macmillan nurse, the specialist lung cancer nurse and the respiratory ward sister, reported the view that it was inappropriate to mention benefit and compensation claims at the same time as disclosing the diagnosis. One nurse recalled that patients who had just received shocking news of their fatal illness were not able to absorb additional complex information regarding benefits and compensation during the same consultation, 6.7.1, 6.7.2. However one physician reported an alternative view: he felt that on some occasions, knowing about the potential financial claims gave relatives the task of obtaining due financial benefit and that in some cases this may have helped to deflect relatives' anger.

The complexity of both the state benefit system and the civil compensation process was emphasised by several nurses who were often put in the position of being the people to whom patients turned to for advice. Although the nurses were in general agreement that they should not function as benefits or legal advisors, and this was apparently confirmed by their managers, they reported that it was essential that they understood the details of the claims processes in order to assist patients to obtain their correct financial entitlements, 6.7.2. The helpline nurse described that she had taken on the responsibility for educating nurses via the Mesothelioma Nurses network about these issues because they mattered a great deal to patients and their families. The Macmillan nurse also noted the burden of financial matters on patients and their families, 6.7.3, 6.7.4, 6.7.5. Doctors' lack of detailed knowledge of the criteria for civil compensation on the basis of occupational disease was also highlighted by the helpline nurse. She reported that incorrect advice to claim compensation was sometimes given by consultants to patients. For example, in giving incorrect advice to pursue a claim in cases when there had been no history of industrial exposure to asbestos, 6.7.2. Patients' motives for claiming compensation were described by the helpline nurse as relating to retribution rather than financial gain, 6.7.6. Contrastingly, the GP recalled how some solicitors were actively recruiting

clients from sessions they held in his area in working men's clubs and referred (in all seriousness) to this as being 'good for [the solicitors'] business' 6.7.7

### **Box 6.7: Explaining state benefits and civil compensation**

1. *'...straight away almost , pretty soon after diagnosis, they're given information about pursuing claims and things...And I find I really don't know what to say to them, because part of me feels that yes, I know they need to know about this but they've just been told, you know, some devastating news, and as nurses we kind of want to look after them ... you feel as if they are being told "Ah well, you've got that but you can make a claim" you know, it just doesn't compensate, does it? And I do find that, as a nurse, hard, following diagnosis.'* Respiratory ward sister

2. *'As a nurse I was quite firmly told "You do not give legal advice" ...but I need to know if the patient has been given the correct legal advice, so you've got to know a certain amount about the law...it is very complicated. So... I suggest to people that they should see a specialist solicitor if I can obviously identify that they have had occupational exposure, and they should be aware they may have a legal case. Often they're given the wrong legal advice by the consultants, in actual fact. I get a lot of patients who are told "You've got mesothelioma, this is a compensatable disease" and then you find that the patient has absolutely no history of asbestos exposure at all, and they haven't got a compensatable disease...you have to use your common sense...the other difficult issue is about benefits, because we're not benefits advisors either, but if the specialist nurses don't key people into other services then they don't know... again it's complicated for the mesothelioma patients because they are entitled to industrial benefits if they've been exposed in their occupation, so a lot of my teaching to the nursing teams...was about those issues that they didn't know anything about – the legal position and the financial position...I mean the patients can also claim a government grant if the firms are out of business...if they didn't know about that it could actually cost thousands, it's absolutely vital that they know.'* Helpline nurse

3. *'The [ Mesothelioma Network] nurses came up, had a full study day with me and I imparted every bit of information I possibly could to them...I devised a resource file which they took away with them, so if they got questions that they couldn't answer they'd find the answer in the file, because a lot of the queries are outside the normal nursing knowledge...about...benefits and compensation, the legal issues, and the nurses needed to know enough to know how to guide the patient to the next step.'* Helpline nurse who started the Mesothelioma Nurses Network

4. *'...a lot of them come from... a very low socio-economic group and to just get them £50 a week makes a big difference to their health.'* Lung cancer clinical nurse specialist

5. *'the big thing is obviously the financial side of things which obviously causes a lot of stress.'* Macmillan nurse

6. *'There was a lot of anger about it, a lot of feeling of injustice, I think, that affected their mental...the way they coped with it, and a lot, they didn't go for compensation claims because they wanted the money, it was like a way of saying "Somebody's got to pay for this" you know, the motives behind it were not greed or anything.'* Helpline nurse

7. *'Well I think the legal advice is there, I think economically speaking for the solicitors it's Good business and there are some regular little clinics they set up in working mens' clubs and things, where people can contact them for advice.'* GP

## 6.9. Involvement with family carers

*'...they wanted to be one step ahead'* Helpline nurse

### 6.9.1 Care of family members during the patients' illness

Carer support appeared to be seen as primarily the responsibility of nursing staff, particularly Macmillan and district nurses. As mentioned in the previous section, nurses appeared to be responsible for expanding on information about the disease, state benefits and civil compensation, as well as arranging practical support, and liaising with other professionals and agencies as necessary. In most cases this was done with the involvement of family members. Hospital doctors all offered patients the opportunity of being accompanied by a relative, particularly when diagnosis was disclosed. However their involvement with relatives at other times seemed to depend on relatives' requests: no one reported any systematic approach to addressing relatives' needs or any acknowledgement that hospital doctors had any responsibility towards patients' relatives.

However, in GP, community and hospice settings, the relatives seemed to be automatically included in consultations with patients from the outset. The GP recalled that he usually knew the patient's family and ward and community nursing staff reported that they actively engaged with patients' families. Community nursing staff reported that they usually visited patients at home with the exception of the nurse-led palliative care service in one location which ran an outpatients clinic<sup>88</sup>. Anger and anxiety were reported as common reactions in relatives (as well as in some patients) but no specific measures to address this were reported, 6.8.1. The need for family carers to have information that enabled them to plan ahead was described by the helpline nurse and that practical advice was also requested. A particular anxiety for relatives concerned the expected mode of death and the reports from nurses demonstrated that relatives turned to nurses to answer these queries. The helpline nurse recalled that she signposted carers to other agencies that could assist them and informed carers of their own entitlements although she recalled that many

<sup>88</sup> Described later in the section on service issues, p239.

carers were too busy looking after the patients to take their own needs into consideration, 6.8.2, 6.8.3.

It appeared that no one had the responsibility for making sure that relatives know about the post mortem and inquest before the patient dies: an unresolved situation regarding informing relatives about the coroners procedure was reported by several professionals, 6.8.5 – 6.8.7. Several professionals recalled relatives being distressed when told about these procedures immediately after the patient had died. The general view reported was that relatives should know beforehand (Human, 2002). In one area, as described by a Macmillan nurse and palliative medicine consultant, a system to ensure this matter was addressed had been introduced. In other cases, particularly with the other hospital consultants, the issue appeared not to have occurred to them as being their responsibility, whereas the GP felt that most families in his area would already be aware of the coroners investigation from legal advisors and therefore did not specifically ensure this was understood in each case prior to the death of the patient, 6.8.8. Both the helpline nurse, through the Mesothelioma Nurses Network as reported earlier, 6.7.2, 6.7.3, and the lung cancer specialist nurse, 6.8.7, reported that they regarded educating nursing colleagues about these issues as part of their professional roles.

Undoubtedly support for carers was seen as the responsibility of nurses. The doctors' role was limited to seeing relatives when they accompanied the patients. In most instances, relatives appear to have been seen as secondary to the patients during the patient's illness. This illustrates the disease focus of health services and yet, if patients are going to be cared for at home as much as possible and to achieve their wish to die at home, carers' issues must be understood (Smith, 2001:83-99; Hinton, 1994). The complex responsibilities that the carers' role entails are well-reported (Payne and Ellis-Hill, 2001) but health policy has only recognised this in recent years (Carers (Recognition and Services) Act 1995).



### Box 6.8: Care of family members during the patient's illness

1. *'And because diagnosis takes longer and investigations take longer, there can often be a lot of anxiety and anger that comes from the relatives, not the patient.'* Respiratory ward sister
2. *'So how people would actually die, the process of how it was going to be was quite an issue with the carers, they wanted to be one step ahead...to be able to plan mentally for the next thing they were going to have to face...and they wanted to know how that progress was going to affect the life of the patient, so we had quite commonly discussions about how you could be one step ahead at home...how to make sure you've got a good handrail on the staircase...simple things that would make life manageable...for the carers that was a big thing.'* Helpline nurse
3. *'...the relatives, you know often they will ask you how their loved one is going to die, because they've not seen people dying before... and they are quite frightened by that. And to just explain to them that someone is going to go to sleep more and be quite comfortable, and very few people have a horrendous death, gives them comfort as well...'* Lung cancer nurse specialist
4. *'Exceptionally if relatives have got unfinished business that they need... they will sometimes make an appointment and I have seen bereaved relatives of mesothelioma...'* Respiratory physician
5. HC: *'Can I also ask you about informing the relatives and the patient about the Coroner's investigation after death – is that part of the routine?'*  
*'It's not, actually. It is a bit tricky isn't it?'* Respiratory physician
6. HC: *'What about informing relatives in advance about the medico-legal procedures after death?'*  
*'Well we tried to do that and explain to them, but actually I think by the time they came to us their knowledge of the situation was generally fairly good... but that would have been part of our management, to make sure that that happened.'* Palliative medicine consultant
7. *'I try to take the families by and tell them that it will be a notifiable disease, even though we haven't got histological diagnosis, that it will go to Coroner's court. That's a terrible time for the family, they want to have that saying goodbye, and have that ritual of the funeral. Also that they will take specimens... I don't tend to go into the details of what will happen at an autopsy unless I am really pushed, because to describe that graphically to someone can be very upsetting to them. But I always try and prepare them- they are not going to get the death certificate, they can't register the death, and try and guide them through that, and I try to go in, usually as soon as the death has occurred... but funeral directors are usually brilliant with them as well.'*  
HC: *'Is that job left to you then, to inform the families generally?'*  
*'I've not known of a doctor go through it and I don't know how many nurses do...and if I'm teaching other nurses, to go through the legality issues with them and explain that relatives often just want to know the obvious.'* Lung cancer nurse specialist
8. *'...usually sufferers from mesothelioma have had legal advice beforehand so the relatives are prepared for what's going to happen.'* GP

## 6.9.2 Care of family members in bereavement

Bereavement following mesothelioma was perceived by several professionals as complex: they recalled that many relatives were angry and that the grieving process was often hindered by the inquest and ongoing civil compensation claims, 6.9.1. Interviewees recalled that the anger evident in relatives may have been obvious throughout the illness or in some only became apparent after the patient had died. The GP recalled bereaved relatives as being '*haunted*' by distressing memories of uncontrolled pain, 6.9.2. As mentioned in the previous section, all the palliative care or nursing professionals were in agreement that relatives should be prepared for the coroner's medico-legal investigation before the patient died. Several respondents recalled the distress caused to relatives when they had not been forewarned. The post mortem and inquest were perceived as having a negative impact on funeral and grieving rituals; in particular, some relatives had to endure many months delay awaiting an inquest. There appeared to be no single routine regarding the care of bereaved relatives. Macmillan nurses generally visited relatives after the death of the patient, while the GP reported that he waited for the relatives to call on his services rather than visit routinely. Hospital consultants did not see bereavement support as part of their role and reported that they rarely saw relatives after the patient had died unless there was some major unresolved issue. Hospital systems for dealing with the death certificate were reported to tend to prevent bereaved relatives from visiting the ward where the patient had been cared for and so further contact with hospital nursing staff was unlikely, 6.9.2, 6.9.3.

Macmillan nurses regarded their role as including bereavement risk assessment. This involved identification of relatives that would need particular support in bereavement and referral to specialist services appropriately. Although in some cases the Macmillan nurse used a bereavement risk assessment tool this was not routine and did not appear to be considered by the other professionals, 6.9.4. Two of the interviewees, the palliative medicine consultant and the lung cancer nurse specialist, working in the same area, described having access to a coordinated, partly NHS-funded bereavement service, 6.9.4, 6.9.5. In most cases interviewees described a range of charitable services that varied in scope and scale; several healthcare professionals commented that bereavement services were underdeveloped. Two interviewees

mentioned that asbestos disease support groups may help in bereavement, for example, by involving bereaved relatives in campaigning activities.

Primary care support for carers after the death of the patient appeared to be equally uncoordinated: the GP saw people who presented to him, and, although the Macmillan nurses reported that she usually visited the bereaved relative for a variable time after the death, there was no consensus among those interviewed regarding the provision of support for bereaved relatives. Similarly, across the three sites, the provision of formal bereavement services was variable and depended on both charitable and NHS providers. This reflects the controversy about the place of bereavement support with respect to health care: on one hand bereavement is regarded as a natural process and therefore should not be 'medicalised', on the other hand, people who are undoubtedly suffering from severe or abnormal grief reactions need access to a professional service.

Many of the issues raised in this section have been addressed in the recent publication: *'When a patient dies: Advice on developing bereavement services in the NHS'* (Dept of Health, 2005). This document advises that all hospital Trusts should develop systems aimed at supporting relatives of patient and has been developed following recommendations of two public enquiries<sup>89</sup>. The document sets out best practice guidance and includes core principles, practical steps and examples of best practice for Trusts to follow. Specific issues relating to bereavement due to mesothelioma are raised in Chapter 7, Discussion, p295.

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<sup>89</sup> The Alder Hey enquiry concerned the 'body parts scandal' (Burton and Wells, 2002) The Bristol enquiry related to excessive deaths of children undergoing cardiac surgery (Bristol Royal Infirmary Inquiry, 2001).

### **Box 6.9: Care of family members in bereavement**

1. *'For a lot of them, if they are taking legal action it's not completed by the time the patient dies, the action is still ongoing, so there is no...they can't close, it's still ongoing, they're still having to be involved in the litigation...The other part is... the post-mortem, the Coroner's inquest, everything delays their sort of bereavement process, and I think the anger is there...because they've lost their husbands, wives....And they don't grieve as straightforwardly, I don't think, and I think that's what prompts the calls, and I get quite a lot. Usually these sort have anger, want to be active, want to do something, either to help others or to help any of you that's doing research into it, or something, they want to get involved because of the anger that's still around, and I just think it delays the normal grieving process so they do tend to be around quite a while, it's not unusual to get calls quite a long way on, and to get things like donations, like I got this week from somebody whose husband actually died 3 years ago.'* Helpline nurse

2. *'...we let them spend as much time as they like with the dead relatives, but once they've left the ward they needn't then return if they don't want to. Some families find it difficult to come back. The relatives go to the bereavement office to get a death certificate...they can come to the ward to collect property'* Respiratory ward sister

3. HC: *'Do you routinely see relatives afterwards?'*  
*'Yes, I mean...usually the widow will come and see me a few times afterwards and we'll just talk through things...what I would say, from the small experience I've got of this, is that it's sometimes very difficult to get people over having seen their husband in severe pain; that tends to haunt them afterwards, and that can be difficult.'* GP

4. HC: *'Would you feel [the bereavement service] should be there as part of NHS provision?'*  
*'I think so, but do you have a generic bereavement service that covers everybody or do the community Macs [Macmillan nurses] run a service for their patients, or do the hospice run it? ... It's a very complex sort of thing... they'd amalgamated, I think, CRUSE\* and...it was a coming together of several agencies, I think, under one roof...and that did seem to work well.'* Palliative medicine consultant

5. *'We have a very good bereavement service... it's run by the Chaplain service as well as trained bereavement counsellors...everybody who dies in the hospital will be met by a bereavement counsellor on the day they pick up the death certificate...if they are known to the Macmillan team who have worked with them we will do up to 6 bereavement visits and then pass on to the bereavement service. Anybody who dies at the hospice [the relatives] are invited to a bereavement group...that's not always appropriate for someone who's bereaved, they don't feel like going to a group and sharing those thoughts and feelings. Some are very depressed and just don't want that sort of contact, but they are also referring to bereavement.' ...I try and screen for depression as well, and try and get them into the right services, and I realise that my role has to stop and move on, and I need to channel them into the right support really.'* Lung cancer specialist nurse

\* CRUSE is a national bereavement charity

## **6.10. The emotional impact of caring for patients with mesothelioma**

Mesothelioma was reported by all the interviewees as affecting them emotionally. Many negative feelings were expressed illustrating the hopelessness of the situation. In general, difficulties were perceived to be associated with mesothelioma because it is a rapidly fatal, preventable, highly symptomatic, untreatable disease. Doctors described how they felt impotent and despairing at having no effective treatments to offer, and being unable, in many cases, to achieve good control of symptoms. Dealing with the psychological suffering of patients and their families was also upsetting for the healthcare professionals. Many interviewees appeared to share the distress of patients and their families: their accounts illustrated that they became fond of many of the patients and their families and found watching the inevitable decline of the patient very upsetting, 6.10.4. Nurses in particular frequently developed close relationships with patients and their families over the course of the illness, 6.10.1, 6.10.2.

All the professionals referred to anger that was evident in this group of patients and/or their relatives. They perceived that this was particularly notable in mesothelioma compared to other illnesses, 6.10.3. Managing their own emotions as well as trying to help patients and their families cope with their reactions was particularly an issue for the nurses who were likely to be closest to them, 6.10.5, 6.10.6. One interviewee referred to his view that the risk-accepting culture of some of the occupations involved possibly engendered a stoical response in patients and he contrasted this with the desperation and fury of relatives. All revealed their sympathy for distraught relatives who felt the need for blame and retribution and although it was reported as hard to bear when relatives' anger was directed at healthcare staff (see Box 5.7), this was sometimes linked to relatives' difficulties in accepting the lack of effective treatments, 6.10.5, as also described by bereaved relatives in the focus groups (Box 5.6). The healthcare professionals expressed their compassion and understanding of this situation. Some healthcare staff expressed their distress at having to watch the inevitable decline of patients; one physician revealed that he also felt angry on behalf of the patients, others were upset by the lack of evidence for best practice and system failures that disadvantaged this group of

patients; concern was also expressed about the future toll of asbestos-related disease and the situation in resource-poor countries where asbestos industries continue, 6.10.6, 6.10.7.

The effect on healthcare professionals of caring for patients with mesothelioma has not been previously described. The data reported here reveal that professionals are distressed by the experience of dealing with people suffering from this avoidable fatal illness that causes much suffering and for which doctors have no effective treatments. In contrast to studies of other cancers, particularly lung cancer, in which the psychosocial needs of patients are said to be ignored or unrecognised, (Krishnasamy and Wilkie 1999:100-102), it was apparent in this study that the emotional, financial and medicolegal needs of patients with mesothelioma were considered from the time of diagnosis. This is probably related to the need to proceed with civil compensation claims while patients are well enough to do so. It also relates to the need to establish causation for specific State benefits. The consultant is invariably required to provide a formal medico-legal report in order to support litigation.

It may be that the inability to offer any standard effective treatments in mesothelioma removes the 'distraction' of concentrating on life-prolonging measures: patients, their relatives and healthcare professionals may then become united in helplessness. Although most of the patients in this study appeared to react to the illness with stoicism, (Box 4.9, p149), many of the professionals referred to the anger evident in patients' relatives. As a particular feature of mesothelioma, this must make emotional issues hard to ignore. Similarly, witnessing the inevitable decline of patients and feeling impotent may leave professionals vulnerable themselves as this undermines their professional role. In this situation it is possible that the doctor-patient relationship is based on the need for support rather than expectations of specialist treatment.

The risk of burn out in professionals who deal primarily with patients who are dying is well known and, to some extent, the nursing profession has addressed this with adopting clinical supervision, but this is not a concept familiar to doctors. This raises the question of care for those professional carers who, from these data, are placed in a very demanding and distressing situation when looking after patients with mesothelioma and their families.

**Box 6.10: The emotional impact of caring for people with mesothelioma on healthcare professionals**

1. *'I think the main thing with mesothelioma, the real difference is that you get this diagnosis, you get a sinking feeling when you see people with chronic pleuritic chest pain who've worked with asbestos, and then they go up to the hospital and they just come out with no prospect of a cure.'* GP
2. *'And then following up patients and watching their progress and watching them coming to terms with their failing health, with at the same time all the other things going on, the legal cases, coming to terms with their situation, which they don't come to terms with very quickly because of the nature of the disease, it's a slow progression.'* Respiratory physician
3. *"Why is this happening to me?" That happens in all diseases but I think they're more angry because they think "This shouldn't have happened to me, this is a preventable disease".* Thoracic surgeon
4. *'One of the things that I think is a bit different is, I don't know how other people feel about this, but something you mentioned, the patients and family being angry, I think it makes me angry as well: if someone has something they've developed as a constitutional vulnerability then fair enough, but it does make you very angry, and I share that with [them]...so it is particularly troubling to deal with the carers for health care professionals...There's something about the dynamics of the disease as well, the slow progression with everyone knowing what's happening, and you get to know them and you see them gradually failing and deteriorating, it is very distressing.'* Respiratory physician
5. *'I don't think the patients are particularly demanding on the nurses, but I find the families are probably more so. They seem to have a lot more anxiety, probably anger as well, and sometimes that can be inflicted on the nurses, to be honest.'* Respiratory ward sister
6. *'...Oh, I thought it was terrible. It was heartbreaking. Patients that would phone you up and ask if they could come in, and in the past you'd be able to say "Yes, we've got a bed, come on down" you have to say "I'm really sorry, you've got to go to A & E" and it was awful. It took a lot of time to get your head round it, to be honest, because you just felt like you were turning patients away.'* Respiratory ward sister upset that patients no longer had open access to her ward
7. *'...But I also feel there's a political agenda here, that it is an occupational disease, it is going to be increasing in the future years, the next decade, and even though there were laws passed, was it adhered to Health and Safety regulations? They're still mining it and using it in part of the... you know it's big business and they're there really to make the voices of the people quieter, and I feel that we do them a great disservice, that they need a lot of support and experienced specialist palliative care, these patients.'* Lung cancer clinical nurse specialist

## 6.11 Service provision

### 6.11.1 Community care and mesothelioma

*'...so you're immediately into a palliative care situation...'* GP

Responsibilities for the care of patients when at home were reported as resting mainly with their GP, district nurse and Macmillan nurse, usually in liaison with hospital colleagues. The relationship between these professionals was reported to be crucial and specialist nurses described being aware of the sensitivities around professional roles and responsibilities although relationships were generally reported as good, 6.11.1, 6.11.2. The particular needs of patients with mesothelioma were also illustrated by the GP who reported that, although not critical of out-of-hours services, he nevertheless gave his patients with mesothelioma his home telephone number so that they could call on him at any time. However this GP also reflected that, with the development of specialist palliative care and hospice services, his role in caring for patients with mesothelioma had been diminished. He qualified this by conceding that he had neither the time nor the resources to provide the same degree of care himself, 6.11.3. In one unusual case, the patient was supported throughout the course of his illness by a lung cancer nurse specialist working for a combined Trust<sup>90</sup>.

Several interviewees expressed the opinion that patients with mesothelioma need specialist care in the community due to the complexity of their symptoms. The need for additional resources for community nursing and palliative medicine specialists was reported by three interviewees, 6.11.4. In one area where there was a vacant post for a consultant in palliative medicine, a clinical nurse specialist described an innovative nurse-led hospital-based palliative care clinic to which patients and families could self-refer. The nurse recalled with some pride that this model had been so effective in fast-tracking symptomatic patients to clinics that she hoped it would be extended to other areas, including the community, 6.11.4. She reported that this development was due to her employment by a combined Trust which had also improved communication across boundaries and allowed her to keep track of patients more efficiently. The need to be proactive in caring for patients with mesothelioma, because they

<sup>90</sup> A combined trust is an amalgamation of a Primary Care Trust with a Hospitals Trust.



may deteriorate very quickly, but tend to be undemanding of services, was also emphasised by the clinical nurse specialist, 6.11.4, 6.11.5.

Additional issues concerning lack of equity of community service provision, particularly affecting rural areas or those distant from a regional cancer centre were recalled by two interviewees. Inconsistent services in different areas were also highlighted: district nursing was not universally available 24 hours a day, and hospices services varied too, 6.11.6. The importance of siting services appropriately was raised by three interviewees. The need for patients to be cared for in a specialist setting was raised by the consultant in palliative medicine: he needed to admit patients to a hospice when complex drug regimes were to be introduced. The lung cancer nurse specialist reflected on the lack of local and community-based services. The practical difficulties for very breathless patients in trying to attend clinics was raised by the Macmillan nurse who was wondering if a community- or home-based breathlessness service might be more practical than one held in a hospital, 6.11.4- 6.11.7.

### Box 6.11: Community care in mesothelioma

1. *'So you're immediately into a palliative care situation...saying "Well, OK, we can't cure it but let's see what we can do about the symptoms, you shouldn't have to suffer" and then you've got to try and deliver that.'* GP
2. HC: *'And how strong or weak are your links with actual GPs?'*  
*'Very very strong... I know which ones to pick up the phone to, which ones I need to go and see personally...But that's taken a few years to build those relationships and trust up, and it's basically the person in the post going and seeing them, explaining the role.'* Lung cancer specialist nurse
3. *'I think we're quite lucky in this area... really well blessed with good back up from the hospital, but I think palliative care, the hospice, the [consultant in palliative medicine's] and the oncologists work fantastically with [the specialist palliative care] team...I was a Trainee in North Wales...we had a Cottage Hospital there...we did all our own palliative care, there was very little Hospice use... as a GP, it's quite a rewarding thing to do, palliative care, and to a certain extent it's taken out of our hands by the hospice. But my experience of the Hospice is that it does a far better job than I could ever do, I just don't have the time or the resources to do what they do...'* GP
3. *'We run a nurse-led clinic...patients can refer themselves in...if there's a problem we've got a thoracic surgeon, an oncologist, and a general chest physician to see them and we get them admitted, and we do letters to the GP...that has stopped patients having problems getting clinic appointments if they feel ill...families can come to clinic and it has been extremely popular. Now we're trying to move that model out so we get it at the local district generals, and maybe into community as well, and get the palliative care team in.'* Lung cancer nurse specialist
4. *'...sometimes I will say to patients in clinic "I will ring you" or "I can come out and see you"...I have had patients who said "I felt so wretched I couldn't pick up the phone to ring and ask for you to see me" So that made us think of working in a different way.'* Lung cancer nurse specialist
5. *'...the majority of these patients spend 90% of their time at home, so we should have the services out there...we need more community focus... There's a palliative care/pain clinic at [another] hospital but it's difficult to ask somebody with pain to travel 50 miles round trip ...they need to go for the local services, and those services can't be provided at the moment in community. Some hospices don't even do blood transfusions so you have to get them to your local hospital. And often mesothelioma patients are feeling so unwell, to make them travel anyway, can be too much for them... ... it is very difficult to get services out to the rural communities...if we get a call to go to a patient, it may not be that day...we're spread very thinly.'* Lung cancer nurse specialist.
6. *'A typical patient would be referred for difficult chest pain, and I would try and get them in to the hospice, generally, because if you're going to start complex regimes you want to keep an eye on them, you want people around that are not fazed by using unusual agents...'* Palliative medicine consultant
7. *'...they were talking about a 5-week [breathlessness] programme...but if someone's poorly they don't come! Is it better to see the patient wherever they might be for 5 weeks?'* Macmillan nurse

## 6.11.2 Hospital care and mesothelioma

*'...it's nice to have the multi- disciplinary approach'* Respiratory physician

In the hospital setting, there was general agreement amongst the professionals that the introduction of MDTs, (multi-disciplinary teams), had improved the care of patients with mesothelioma and led to more consistent management. In particular, it was reported in one area that this had significantly reduced the waiting time for prophylactic radiotherapy thus complying with advised practice, (BTS 2001). In another area it appeared to have improved recruitment into clinical trials, 6.12.1-6.12.3. However, some disappointments with the multidisciplinary approach were reported: several interviewees reported poor access to specialist pain services and palliative medicine consultants. In two areas there was reportedly lack of a clear lead doctor for each patient that appeared to have led to some confusion regarding role boundaries. This had apparently been resolved in the third area with agreement that the patients would be jointly managed by the respiratory physician and oncologist who would refer to others if necessary, 6.12.4, 6.12.6, 6.12.7. Interestingly, none of the other hospital specialists mentioned palliative medicine as an integral part of the lung cancer MDTs, although two referred to the benefit of having clinical nurse specialists involved.

Recent changes in hospital services were reported as causing disadvantage to patients with mesothelioma: it was reported that national performance indicators and targets such as the maximum four-hour stay<sup>91</sup> in A and E departments, (Department of Health, 2000a), resulted in patients with mesothelioma being admitted to any ward rather than directly to the respiratory ward as had happened previously. The ward sister recalled that it disadvantaged patients to be admitted to wards where they were not known and where staff had no particular expertise in the management of mesothelioma. She also regretted the loss of the previous 'open access' arrangement where patients had referred themselves to the respiratory ward when, for example, they knew that a further pleural aspiration was needed, under the latest system she reported that patients requiring urgent pleural aspiration may wait for some hours in A and E

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<sup>91</sup> A and E departments risk financial penalty if patients are in the department longer than 4 hours. This target was introduced in order to improve patient waiting times in A and E as part of the NHS Plan, 2000.

before being admitted to any ward; her distress regarding this situation was obvious. A further change that was reported to disadvantage patients was reported due to rearrangements of chemotherapy services as recommended in the NHS Cancer Plan (Department of Health, 2000b) with the intention of concentrating specialist services in centres of excellence: the respiratory ward sister reported that whereas they used to administer chemotherapy on her ward where patients with mesothelioma were known to staff, this facility had now been moved to another hospital, some miles away, 6.12.5.

Healthcare professionals reported that patients with mesothelioma need easy access to specialist help across a range of specialities, particularly respiratory medicine and specialist palliative care, as these dealt with the major symptoms of breathlessness and pain. Respondents related this need for specialist care to the erratic disease trajectory including emergency admissions due to pleural effusions, an appreciation of the challenges of symptom control and an acceptance that expert knowledge of mesothelioma is patchy. In one area, delay in referral to palliative care teams from chest teams was cited as causing poor symptom control for patients, although the situation was perceived to be improving due to the appointment of a new respiratory physician whose policy was to refer to palliative care at the point of diagnosis, 6.12.6. In another area the lung cancer nurses tended to refer patients with mesothelioma to the palliative care team only in the final stage of the illness, 6.10.7. Two respondents referred to the national shortage of consultants in palliative medicine and this affected the working practice of the respiratory consultant. He felt that he had to operate outside his area of expertise in providing symptom control for his patients with mesothelioma in the absence of a consultant in palliative medicine, 6.12.8. The lung cancer clinical nurse specialist, working in the same area, reported an innovative nurse-led palliative care service that she had developed in the absence of a consultant in palliative medicine (described in Box 6.11).

Patients with mesothelioma were reported to attend several hospitals, some at considerable distance, in order to access oncology, radiotherapy and thoracic surgery; this was difficult when patients were frail or symptomatic. In one area, where patients had to travel 80 miles to the nearest thoracic surgery centre and around 70 miles to the nearest radiotherapy centre, it was reported that this

caused additional physical and emotional distress for patients with mesothelioma, 6.12.9.

#### **Box 6.12: Hospital care and mesothelioma**

1. HC: '*...Lung Cancer MDT? Do you think that has been a helpful development?*'  
'*Absolutely. I think we are now looking at probably 98% of all lung cancer and mesotheliomas in one meeting with the radiologists, oncologists, surgeons, cytologists and everyone else...the radiotherapists, so all these patients are discussed and treated appropriately.*' Thoracic surgeon

2. '*... it's nice to have the multi- disciplinary approach...with the input from the oncologists and the surgeons speaking to each other so they get prophylactic radiotherapy in time...the lung nurses as well, which is particularly important.*' Respiratory physician

3. '*We always try and get the radiotherapy to the biopsy sites done within a 6 – 8 week window...that's really a strength of what the MDT's done.*' Lung cancer nurse specialist

4. '*...the thoracic surgeon won't follow them up, apart from the exceptional patient who at has early disease, they will obviously follow them up...but most of the patients would be shared follow-up with oncology and respiratory medicine.*' Respiratory physician

5. '*...when patients come in to A & E they're just found a bed, we're not able to keep beds free to get our mesothelioma patients up here, so wherever there's a bed in the unit, there are 2 other wards, they go to wherever the bed is. We do try and get them up here but... management and bed co-ordinators don't always let us...We used to have a self-referral list... mesothelioma were on this list...if they felt unwell they phoned the ward and if they had a bed, in you came...that was stopped because of management and they had to go through A & E like everyone else...they could be sat in A & E for hours....Now you just get a co-ordinator who says "A bed's a bed, and trolley waits are piling up' ...but then they end up on a ward that isn't specialised in their problem, so the hospitals stays are doubled because you can't get a consultant to come and see you, the medics on that ward aren't specialised so they've got to refer on...It's all in response to government wanting star ratings... We used to do chemotherapy here... that got taken as well...another political...'*' Respiratory ward sister

6. '*I think that patients fell through the net...kept by the chest team, not referred to palliative care 'til very late in the day and they already had had months of symptoms...that side of things has improved....and the referral into Macmillan is now better than it was...'*' Macmillan nurse

7. '*Usually mesothelioma patients see a lung Macmillan nurse in the primary stages. Of course at the end they would see palliative care. And one of our lung nurses is very interested in mesothelioma...when they are in hospital she always picks them up very early on...I haven't known any mesothelioma patients in my experience be referred to specialist pain services.*'

HC: *So things like nerve blocks, spinals, epidurals?*

'*In my experience I don't know of any of those being done with our patients...'*' Respiratory ward sister

8. '*Well I do feel that we should have more specialised palliative care, these patients are terminally ill and whilst I've been happy to deliver that sort of care it's not perhaps the totally optimal environment, so I would perhaps want to see more palliative care, but that also goes for our lung cancer patients actually.*' Respiratory physician

9. HC: '*So how many hospitals would your local patients be accessing?*'

JB: '*[Three] and then there's 2 hospices as well, covering those areas...They go to the General for biopsies and pleurodesis...[hospital] for radiotherapy, chemotherapy.*' Lung cancer nurse specialist

### 6.11.3 Improving standards of care

*'There's no clear cut protocol or pathway that these patients should follow... it would probably be nice to standardise.'* Thoracic surgeon

The lack of clear guidance as to best practice was raised as a problem by two professionals but, when asked, interviewees found it hard to offer personal definitions of best practice. Most responded with reference to their own speciality rather than taking an overview of the care of patients with mesothelioma. The exception was the palliative medicine consultant who included medico-legal and emotional issues as well as symptom control, however he limited his reply to patients who were not having active treatments. There was recognition that best practice would need to encompass early diagnosis, symptom control, emotional reactions, timely access to appropriate services, financial matters and medico-legal issues, 6.13.1, 6.13.2. Although access to specialist pain services was seen as ideal it was reported to be inadequate in two of the three areas. The palliative medicine consultant, who had access to a specialist pain service, appeared to feel that it did not meet his expectations, 6.13.3, 6.13.4. As discussed later (p249), several professionals stressed the need for individualised care and that services need to be easily accessible and responsive to sudden changes in the condition of patients.

Specialist nurses were valued, particularly those with additional training in mesothelioma, although it was recognised that there was a need to clarify roles and responsibilities. The difficulties in attempting to create a mesothelioma nurse consultant post in order to achieve improvements in services were described by the lung cancer nurse specialist: she acknowledged that mesothelioma affects relatively small numbers of patients even in areas of high incidence and that this excluded it from being a health service priority, 6.13.5-6.13.7. However all the professionals affirmed that patients should have easy access to specialist palliative care in all settings from the point of diagnosis.

### **Box 6.13: Improving standards of care**

1. *'I suppose you could cobble together a sort of best practice type approach...So I think it's a case of looking at those other factors, there's the symptom control, which can be, well certainly usually is trickier than average, but then you've got these other psycho-social factors as well, which I think we probably are all aware of and do take into account, but at least in my case not in a terribly organised way!'* Palliative medicine consultant

2. *'That the patients get the help and support they want at the time they want, that they have easy access to that support, that they know where it's available. We really should be there as much or as little as they want, that if they do have a problem...'* Lung cancer nurse specialist

3. *'... the pain service could be better and it could be more accessible, but it's a one-man-band at the moment and you realise that [the consultant] is doing all that he can do, really. But really, yes, in an ideal world there would be a pain control service which we could tap into.'* GP

4. *'...we tend to find with the pain specialists, everyone talks about spinals and blocks and things like that but usually when you get them involved they're reluctant to stick needles in and they do the sort of things we would do anyway, first!'* Palliative medicine consultant

5. *'...it's different to lung cancer...a slightly unique set of patients in a way, in that they have different requirements. The question is who deals with them? I think we now have developed lung cancer nurses who will deal with mesothelioma patients, we also have Macmillan nurses as well, I also get involved with them....I mean there is some good information from, for instance, the solicitors...very much up to speed with what information they offer patients with mesothelioma etc, so I think we're getting better in that we're not sweeping it under the carpet as much as we used to, we can advise patients what their sort of treatment is going to be like and how they are going to feel.'* Thoracic surgeon

6. *'Well, I think earlier diagnosis....and if we had the facilities here to do pleurodesis and biopsy...so patients don't have to travel so far to be diagnosed...I think more streamlined referral [to palliative care team]'* Macmillan nurse

7. *'and when you go to PCTs - and I've tried myself to get a mesothelioma nurse in that area at consultant level so they'd be able to work across and have more influence and structure with them – they will look at those patients, and compared to the lung cancer cases it's still a very small group, but in the country, compared to the mesothelioma it's a very high incidence. And they will say you've got all these people dying of heart failure, respiratory problems, COPD, lung cancer, and we may have a couple of handfuls of mesothelioma patients and you want a full-time nurse at this grade. So it comes to politics and what's able to be provided within the strains on the Health Service, really.'* Lung cancer nurse specialist

## **Summary**

There was universal understanding of the epidemiology of mesothelioma including the relationship with local industries in each site and acknowledgement that patients experienced anticipatory anxiety due to prior knowledge of mesothelioma.

Mesothelioma was usually a small part of the work of healthcare professionals: most were involved in the wider fields of respiratory specialities, oncology or

General Practice. Workload due to mesothelioma, even in these high incidence areas, was generally small. The exception was the 200 contacts per year for the thoracic surgeon who performed investigative, palliative and, occasionally, radical procedures.

Most healthcare professionals in this study believed that patients with mesothelioma were generally fitter than patients with lung cancer. Patients with mesothelioma were perceived as having more severe symptoms, particularly pain and recurrent pleural effusions, compared with lung cancer patients. Pain due to mesothelioma was perceived as complex and difficult to control. Psychosocial issues, acknowledged by all the professionals in the study, were perceived as more severe than those affecting patients with lung cancer.

Healthcare professionals perceived the investigation of mesothelioma as difficult and burdensome for patients and frustrating for clinicians. Obtaining a histological diagnosis was often a lengthy process and not always possible. Staging in mesothelioma was seen as extremely important but technically difficult and hindered by lack of advanced scanning facilities. Prophylactic chest wall radiotherapy, although BTS advised practice after invasive procedures, was often not available within the recommended timeframe. Patients were seen as tolerating investigative procedures with stoicism but perceived to suffer disadvantage due to the disease being relatively rare.

The lack of evidence-based best practice was seen as disadvantaging patients with mesothelioma although standardised treatment plans would oppose the view that patients with mesothelioma require individualised care. Lack of effective therapies tends to foster doctors' involvement in novel and experimental treatments. Healthcare professionals held mixed views about the value of chemotherapy: in general, hospital doctors tended to favour recruitment into trials, whereas those with closer relationships with patients and their families tended to prioritise the negative aspects such as opportunity costs to patients. There are many complex ethical dilemmas surrounding chemotherapy of limited benefit to the individual patient, including inequity of access to palliative care. Ethics of decision-making are involved in giving information to patients about treatments, particularly 'low benefit' chemotherapy. No one advocated chemotherapy outside a clinical trial.



Specialist palliative care was seen as essential in managing patients with mesothelioma. There was no agreement around the timing of referral to palliative care. Symptom control, particularly with respect to pain, was reported as difficult. Under-prescribing and inappropriate prescribing were recalled as common outside palliative care, particularly relating to morphine. Breathlessness was seen as mainly due to pleural effusions, other causes of breathlessness in mesothelioma did not appear to be considered. Doctors viewed pleural effusions as treatable but nurses reported lack of knowledge of mesothelioma, inefficient management, treatment failures and distances to treatment centres as disadvantaging some patients. Non-pharmacological approaches to breathlessness were not utilised. Doctors were prepared to try novel treatments when conventional approaches failed.

Caring for patients with mesothelioma is emotionally demanding for healthcare staff due to the physical and psychological suffering experienced by the patients and inevitable fatal outcome. Doctors felt hopeless and impotent due to lack of effective treatments and difficulties with symptom control, nurses shared the distress of the patients and their families with whom they had often formed close relationships. Anger expressed by relatives was understood by healthcare professionals but sometimes added to their emotional burden. In contrast to reports concerning other cancers, the psychosocial burden of mesothelioma as affecting patients appeared to have been appreciated by healthcare professionals from the point of diagnosis. Clinical supervision is a recognised support mechanism for nurses but not familiar to doctors

Effective care of patients in their homes depends on good relationships between primary healthcare teams, particularly GPs, district nurses and specialist nurses. Specialist palliative care services may lead to 'deskilling' of GPs. Specialist palliative care services are under-resourced in some areas. Combined trust clinical nurse specialists can provide a seamless service for patients. Home-based care may be more appropriate for very breathless patients who find the effort of travelling to and from clinics burdensome.

MDTs had improved access to care (particularly radiotherapy) and increased recruitment into trials but palliative medicine was not usually included in lung

MDTs. The MDT approach may cause confusion over which clinician is 'in charge'. Delays in radiotherapy were common. Target-driven alterations in admissions policies and centralisation of chemotherapy services disadvantaged patients with mesothelioma. There was no policy of referral of patients with mesothelioma to specialist palliative care at diagnosis in spite of several healthcare professionals believing this to be best practice. Long distances, particularly to tertiary centres, were seen as a burden for patients and their relatives.

Healthcare professionals would mostly appreciate the development of best practice guidance in mesothelioma. Best practice should be holistic in scope and recognise that virtually all patients with mesothelioma have incurable disease at diagnosis. Manpower shortages in specialist nursing and medical disciplines, particularly palliative medicine and pain management, were common and disadvantaged patients with mesothelioma. Lack of clarity of the roles and responsibilities of various specialist nursing and medical staff caused problems. Low numbers of patients appears to result in low priority for mesothelioma in health services planning.

Doctors found delivering the 'bad news' of diagnosis of mesothelioma particularly difficult due to the lack of effective treatments, symptom burden and short survival time. Doctors' views around clinical trials varied depending upon whether they prioritised utilitarian or individual outcomes, whereas nurses in general tended to focus on the opportunity costs for individual patients but respected patients' decisions, even if they differed from the nurses' opinions.

There seemed to be tacit agreement about division of labour between doctors and nurses with regard to communication of diagnosis and treatment options to patients: doctors disclose the diagnosis and brief details regarding trials, nurses interpret and expand on this information for patients and their families. This division of labour was not without problems: whereas it relieved senior doctors of some time-consuming, professionally challenging and emotionally-draining interactions with patients, it required nurses to undertake these same tasks and some felt that they do not have sufficient knowledge to do so, others were aware of needing to take care not to contradict what doctors had already said. Nurses expressed some reservations about communications from doctors to

patients but did not appear to voice these concerns to the doctors. Written information for patients to take home after receiving the diagnosis was seen as important. Patients' decision-making about clinical trials was assisted by nurses. Healthcare professionals were aware that patients with mesothelioma may accept risks of 'low benefit' chemotherapy that clinicians would view as unacceptable.

The Mesothelioma Information Service provided information nationally to patients and lay and professional carers and led to the formation of the Mesothelioma Nurses network. The helpline was set up in response to observed unmet needs of patients and families. Patients, family carers, bereaved relatives healthcare professionals, social workers, lawyers and State benefits staff used the service. Different groups of callers needed different types of information. An information booklet was produced as a result of the experience of the helpline nurse. The service provided practical information such as State benefits, civil compensation and travel insurance.

Information about benefits and civil compensation was frequently given at the same time as disclosure of the diagnosis. Nurses were concerned that giving this financial information at the point of disclosure of diagnosis was inappropriate. There was no systematic approach or guidance as to the best time to give the medico-legal advice. Financial entitlements were of major importance for some families. Although nurses are advised that they are not to give advice on medico-legal matters, they need to know of the processes related to mesothelioma in order to assist the patients and their families.

Support of family members was seen as primarily the responsibility of nurses, it was essentially informal and not systematic. The exception was at disclosure of diagnosis when most doctors included family members when breaking the bad news. Specialist nurses were responsible for further explanations of the diagnosis, investigations and treatments to patients, usually with their family carers and also providing them with written information materials. GP consultations frequently included family carers, particularly on home visits. In all cases, care of family members appeared to be considered secondary to the care of patients. Although generally regarded as important that families were

prepared in advance for the coroner's investigation, most services had no systematic approach to this and no one took overall responsibility.

Bereavement after mesothelioma was seen as severe and complex, bereaved relatives were often angry. Medico-legal processes were seen as interfering with grieving and having a negative impact, especially when the inquest was delayed for some time after the death. Care of bereaved relatives varied between the three sites but there appeared to be no single systematic approach. Hospital healthcare staff did not feel they had any role with bereaved relatives.

# Chapter 7: Discussion

## 7.1 Introduction

In each of the previous four chapters I reported the findings from a separate data source: the survey of medical records, interviews with patients, focus groups with bereaved relatives, and interviews with healthcare professionals. In this discussion section I attempt to cut across the boundaries in order to synthesise/triangulate and interpret the findings from the multiple data sources, drawing them together under major headings. The discussion is divided into 6 sections which, taken together, address the research questions that were posed at the start of the study.

## 7.2 Asbestos exposure and risk

### *Occupational exposure to asbestos*

The medical records survey demonstrates a high proportion, (88%), of patients with mesothelioma had been exposed to asbestos at work. This is a higher percentage than reported in most previous studies but reflects sampling bias: this was anticipated and informed my decision to recruit patients in these industrial areas. The high proportion of male patients, 97%, in the medical records surveyed, reflects the gendering of the traditional industries in two of the three locations: the Barrow shipyard and the railways plant at Doncaster. The Leeds situation is different: the workforce in the Leeds asbestos textile factory had a higher proportion of female workers but the factory closed in 1955. It follows that, given the 30 – 50 years latency between exposure and disease presentation, many affected female workers may have succumbed to mesothelioma prior to this study. The patients interviewed and the surveyed medical records relating to Leeds revealed a greater diversity of occupation than the other two sites, but a similar preponderance of men, Table 4.1, page 134.

### *Risk of mesothelioma*

The study revealed interesting and somewhat contradictory findings regarding advice about asbestos hazards at work. Although only two of the 15 patients who were interviewed recalled receiving hazards advice whilst working, about

half the bereaved relatives recollected some prior awareness about the risks of working with asbestos, and most of the healthcare professionals felt that anticipatory anxiety due to prior awareness of asbestos risks was common in patients with mesothelioma. The Introduction, (Chapter 1, section 1.6) detailed the widespread failure of industry and government to act to protect the workforce from asbestos hazards and that this persisted long after the introduction of the most recent Asbestos Regulations in 1969 (Tweedale 2001:159-77; Johnston and McIvor 2000:112-46). Even if hazards advice had been given, it is possible that some patients were reluctant to admit to ignoring advice that may have been literally life-saving if heeded; this strategy might be adopted in order to reduce a sense of personal responsibility, guilt and distress. Hawley *et al* (2004:15-16) revealed a similar finding in Australia: that patients with mesothelioma had 'little or no understanding' of being at risk of mesothelioma in spite of having worked in high-risk occupations at a time when health and safety information was apparently available and the authors commented that health education services 'appear to be failing men with mesothelioma'.

Connell (1996) described the gender effect for men in being less influenced by health promotion advice than women and that this relates to 'macho' risk-taking attitudes and behaviours of young men. It will be interesting to see whether this gender disadvantage persists in British society that is experiencing the rise of what has been termed 'raunch culture' in young women: this includes 'laddish' behaviour such as binge drinking (of alcohol) previously typical of young men (Levy, 2005). This change may indicate blurring of some traditionally-gendered behaviours and attitudes and could potentially alter the different relationships of the sexes with regard to health education. Clearly there is no room for complacency: as carpenters and other construction and maintenance workers are at increasingly high risk of mesothelioma, (Peto *et al*, 2006), it is worrying to reflect on the possibility that asbestos hazards advice, manifestly unsuccessful with regard to the patients interviewed, is probably still ineffective.

This challenging situation relates to what Beck (1992) describes as a 'risk society': our well-resourced western society appears to be intolerant of any risks with an increasingly risk-averse workforce, supported by employers' fears of litigation and the burgeoning health and safety bureaucracy. Beck (1992)

suggests that to live without risk is both impossible and unwanted but that societies need to develop resilience to risk in which realistic assessments of the hazards are accompanied by pragmatic solutions designed to reduce risk to 'reasonable' levels. In Beck's view, society should decide what 'reasonable' is in this context and at present we do not have an obvious mechanism for this type of action.

### *Asbestos, smoking, and lung cancer*

Although many of the patients interviewed had smoked (and 73% in the medical records sample had a history of smoking), it appeared that none of the interviewed patients had appreciated the additional risk of lung cancer due to smoking and asbestos acting as co-factors (Reid *et al*, 2006). However this is mirrored by lack of knowledge in the medical profession: in theory any patient who has a history of asbestos exposure and a diagnosis of lung cancer should be referred to a Coroner when they die because asbestos may have contributed to the cause of death. This could result in more compensation awards being made and would improve the accuracy of asbestos-related disease statistics. This clearly does not happen, probably because many doctors are unaware that asbestos and smoking are co-carcinogens for lung cancer. Asbestos exposure histories are not routinely taken in smoking-related lung cancer cases, and it may also reflect reluctance to refer cases to the Coroner unless there is a legal necessity or clear gain for the bereaved relatives (Hoyle, 2006).

## **7.3 The experience of mesothelioma**

### **7.3.1 The physical experience**

A severe symptom burden was revealed by the patients; bereaved relatives; healthcare professionals and the medical notes survey; the presenting and ongoing symptoms mirrored findings from previous studies (Robinson *et al*, 2005; Yates *et al*, 1997; West and Lee, 2006). The interviews with patients revealed how symptoms were experienced in terms of their effect on daily routines, in particular physical domestic tasks and active hobbies. When these normal pursuits became compromised, patients and their relatives were forced to acknowledge that this was abnormal and at this stage sought medical advice,

echoing Hawley *et al's* (2004) findings. In common with many previous accounts, there was a general reluctance amongst the mostly male and older patients to seek medical advice until symptoms became severe and even then, they frequently had to be prompted by their wives (Gough, 2006).

The reluctance of the patients to seek help could relate to the demographic features of the sample and reflect the undemanding and self-reliant nature of older men who may also have low expectations of physical health and expect to experience some symptoms as they age (Catt *et al*, 2005). It could also represent denial as a strategy for minimising anxiety when there is background knowledge, albeit unspoken, of being at high risk of asbestos-related disease. Gough, (2006), in his critique of assumptions made about men's health suggests that illness, rather than health, is the feminised area. This goes some way to explaining why women may be dominant in illness management but, before illness is established, the masculine model of not seeking health advice dominates. Another related element of hegemonic masculinity is that help seeking implies weakness and vulnerability (Gough, 2006). Interestingly, in a lung cancer study, *younger* patients were shown to be more likely to present to their GP early if they were widowed, separated or divorced, in contrast to the sample in this study; perhaps supporting an age or generational effect (Krishnasamy and Wilkie, 1999: 52). The interviews with patients revealed that their reluctance to seek medical help continued after the diagnosis of mesothelioma and even when severe symptoms were being experienced.

Decisions to seek advice on health matters have been reported as depending on the meanings ascribed to symptoms by patients and their health beliefs around the benefits (or disadvantages) of reporting potentially significant symptoms promptly (Brennan, 2004:56). In patients who may have a background fear of asbestos-related disease, and/or known workmates who have died from such conditions, high anxiety may effectively inhibit action and delay in seeking help may be reinforced by a conviction that, in any case, 'nothing can be done'. This has been described as 'cancer fatalism' and, in conditions where earlier diagnosis results in improved outcomes, is known to adversely affect those outcomes (Powe and Finnie, 2003). A study investigating factors that influence the attention paid to cancer symptoms and the intention to seek advice identified women as generally more active than men, particularly if



well-educated. Other relevant factors were: knowledge of cancer symptoms, perceived agency, perceived advantage in paying attention to cancer symptoms and 'perceived less difficulties with paying attention to cancer symptoms' (de Nooijer *et al*, 2003). Many of these factors would appear to contrast with the characteristics of the majority of (male) patients with mesothelioma.

At present, once a patient with mesothelioma is symptomatic there is no evidence that earlier diagnosis improves survival, although it may enable patients to benefit from more effective management of recurrent pleural effusions and other distressing symptoms. However, earlier diagnosis would prolong the time that a patient and their family are aware of living with terminal illness. The lack of effective treatment, as well as the lack of a reliable non-invasive diagnostic test, lead to the conclusion that, at present, screening for mesothelioma is not recommended (BTS, 2001). This may change as new tumour markers are being identified and if effective treatments become available (Creaney *et al*, 2006).

### *Breathlessness*

The main symptom of breathlessness was described by the patients, bereaved relatives and healthcare professionals, as severe and often refractory. At presentation this was usually due to pleural effusion but later on, as the medical records survey and interviews with healthcare professionals indicate, chest wall fixation and lung encroachment were additional problems. Experiencing breathlessness in mesothelioma is particularly distressing and has multiple complex meanings for patients and their families. Severe breathlessness may represent a life-threatening event; it may confirm disease progression; it may require emergency admission to hospital and invasive procedures; it is physically and emotionally exhausting; it causes anxiety and it may be truly terrifying. It is also highly visible – unlike some other symptoms it cannot be disguised.

Breathlessness also demonstrates one aspect of the 'unbounded' body in which it is obvious to the patient and their observers that previously dependable bodily functions are now out of control (Lawton, 2000:128-33). This adds to the (visible) stigma and to the 'discredit' that has been described as associated with terminal illness (Charmaz, 1983) and contributes to 'loss of self' (Lawton,

2000:133). In previously fit and capable men and women, severe breathlessness reduces them to helpless dependency, which has a devastating effect on identity in terms of agency, role, function and body image (see next section 7.3.2).

Authoritative reports (Bredin *et al*, 1999; Carrieri-Kohlman and Dudgeon, 2005), emphasise the value of a multi-dimensional approach to breathlessness and yet there was no evidence of this in any of the interviews with patients, nor in any of the focus groups with bereaved relatives. Knowledge of such an approach was mentioned by only two of the healthcare professionals, although neither had received training. Breathlessness management techniques have been shown to help patients with lung cancer develop a sense of mastery over breathlessness and reduce the symptom burden. These techniques are cheap, easily taught, 'low-tech' interventions that can be delivered by nurses and physiotherapists, sometimes with contributions from complementary therapists (Bredin *et al*, 1999; Carrieri-Kohlman, 2005).

Lack of strategies for managing breathlessness resulted in relatives feeling helpless and increasingly anxious. This confirms findings of a previous study regarding non-pharmacological measures to relieve *pain* in which relatives learnt by 'trial and error' how simple interventions could alleviate patients' suffering; they did not receive any related information from healthcare professionals (Ferrell *et al*, 1991). The study revealed that where breathless patients and their relatives felt uncertain and out of control, crisis situations occurred frequently and led to panic-driven emergency admissions to hospital.

When there is so little otherwise to offer it raises the question: why are cheap and effective self-help methods of helping patients to deal with breathlessness not part of standard care? It may be that the practice of medicine reflects society's priorities and values and, as a result, inexpensive 'low tech' interventions do not have the credibility of expensive new technologies or medications. Another reason may be that the initial work came from nursing research and that the healthcare professions are still hierarchical with medicine in poll position, resulting in less likelihood of implementation of 'nursing' initiatives. Yet another feature may be that patients (and many doctors) prefer to rely on a 'medical' solution, hoping to cure the problem, rather than accepting

that the best that can be done is for patients to learn to manage their breathlessness. This is one aspect of the 'therapeutic imperative' that drives many doctors to pursue active medical treatments, and encourages patients to believe this is possible, when a palliative approach may be more appropriate, as demonstrated in other end-of-life conditions (Murray *et al*, 2002). As shown in the interviews with healthcare professionals, the doctors (and patients) tended to regard breathlessness as usually due to effusions and therefore readily treatable by aspiration. In many cases this is correct: patients with large pleural effusions do need rapid access to hospital for pleural aspiration and pleurodesis if indicated. However, in general, breathlessness management techniques may reduce some of the associated anxiety, and understanding their problem may empower patients to seek treatment at an earlier stage, thus reducing this particular aspect of the disease burden.

The interviews with patients revealed that, even after aspiration or successful pleurodesis, breathlessness was still a problem, although often less severe. This correlates with the results of a study in lung cancer patients in which breathlessness was found to be the symptom least likely to be relieved (Muers and Round, 1993). Nevertheless, before advocating wholesale adoption of breathlessness management techniques, it must be remembered that the above studies refer to patients with lung cancer and therefore need to be evaluated in patients with mesothelioma; it could be that the presence of physical impairments to lung expansion such as loculated pleural effusions, extensive pleural thickening, and chest wall involvement, as well as other causes of breathlessness such as pericardial involvement, might make these techniques ineffective in mesothelioma. Other factors that may be implicated in breathlessness in mesothelioma are respiratory muscle deconditioning and cachexia. Pulmonary rehabilitation, aimed at maximising lung function, may seem inappropriate in mesothelioma but it might have a place in patients who have a longer than average prognosis – again, this would need evaluation.

Another aspect that this investigation could not adequately answer was raised by the Muers and Round (1993) study in lung cancer that demonstrated neglect of concurrent medical conditions, some of which could contribute to the overall symptom burden. Given the high percentage (69%) of the patients (in interviews and the records survey) who had smoked, it is fair to assume that smoking-

related conditions would be highly prevalent. The medical records survey revealed that 74% of patients had co-existing medical problems: 30% had ischaemic heart disease and 10% had various respiratory diseases and these may have contributed to breathlessness. Examination of medications prescribed for these patients demonstrated a lower use of medications for chronic respiratory conditions than I would have expected. If all the patients whose notes were surveyed had been referred to palliative medicine, the apparent under-use of medication for concurrent conditions may have been explained by the established practice in palliative medicine of discontinuing non-essential medications in the terminal phase, but this was not the case, and therefore this study tends to support the findings of Muers and Round (1993).

In the 1960s Cicely Saunders transformed the management of cancer pain by her conceptualisation of pain as a subjective phenomenon (rather than a strictly physical entity) that required an approach in which physical, spiritual, emotional, and cultural factors were addressed (Saunders, 2001). Her concept of 'total pain' revolutionised the management of pain (and suffering) in cancer and extended it from the biomedical model (Clark, 1999). Perhaps, to paraphrase, the time has come to use the term 'total breathlessness' in order to emphasise to clinicians the multi-factorial nature of breathlessness with the intention of improving its management. A palliative approach would encompass all these areas (Box 1.3).

### *Pain*

Pain in mesothelioma is acknowledged to be difficult to treat due to its multi-factorial nature and attendant psychosocial issues (BTS, 2001; Ahmedzai and Clayson, 2006; Chapman *et al*, 2005). The patients interviewed appeared not to have severe pain at the time of the interview, (not surprisingly, because patients with severe pain would be less likely to volunteer), although several participants had experienced severe pain on occasions. Health beliefs and attitudes may have impacted on admission of pain in the ways described with regard to breathlessness: perhaps pain was minimised in this group of patients and in this instance 'cancer fatalism' would inevitably link pain with cancer. Admission of pain could have implied loss of control; the patients were each interviewed only on one occasion and therefore a trusting relationship with me had not had time to develop and, to some extent, they may have been presenting 'public

accounts' that were based on the image that they wanted to portray to me. It could be postulated that patients who volunteer for research studies gain some 'credit' in terms of an enhanced self-image against the 'discredit' of terminal illness, as mentioned earlier (Charmaz, 1983) and that to admit to suffering, for example, in terms of distressing symptoms, actually undermines their coping abilities and potentially makes them objects of pity and stigmatisation.

The bereaved relatives, of whom only one was related to an interviewed patient, had witnessed severe pain in most cases. This may well reflect sampling issues around the focus groups as it is likely that these were relatives with 'a story to tell' and pain would appear to be a potent feature in 'horror stories' (Vignette 3.1, p115). This has also to be viewed with some caution because opinions differ concerning the accuracy of bereaved relatives' proxy accounts in reflecting the patients' perceived suffering: Higginson *et al* (1994) and Hinton (1996) reveal concerns around reliable reporting of pain in particular, Addington-Hall and McPherson (2001) emphasise that 'memory is a dynamic process' and contextual. The healthcare professionals that I interviewed, in agreement with earlier reports, (BTS, 2001), all recalled experience of patients with mesothelioma suffering refractory pain and agreed that specialist and/or (sometimes unconventional) interventions may be required. Although the literature gives the impression that severe refractory pain is common, my experience, and that of colleagues currently working with patients with mesothelioma, is that severe uncontrolled pain is now relatively uncommon. It may be that, as the discipline of palliative medicine develops expertise in the management of complex pain, patients with pain due to mesothelioma are increasingly accessing a better standard of symptom control.

However, other factors may be relevant: I could not find any quantitative information concerning the incidence of severe pain in mesothelioma and it may be that patients with refractory pain are particularly memorable for their doctors, thus producing an impression of greater numbers than in reality. In this instance I am referring to pain that requires specialist pain management techniques: invasive interventions such as nerve blocks, intrathecal or epidural analgesia, or percutaneous cervical cordotomy. Pain in mesothelioma is usually complex and includes neuropathic components (Ahmedzai and Clayson, 2006). Grond *et al* (1999) estimated that in cancer patients suffering from *neuropathic* pain, 10%

will require spinal analgesia or a neurolytic procedure. The problem of managing refractory complex pain in mesothelioma requires that healthcare professionals should consider early referral for specialist interventions (BTS, 2001; Ahmedzai and Clayson, 2006).

Technological approaches to pain were much more commonly used in the post-war period at a time when there were considerable anxieties about the addictive properties of morphine and when pain was viewed as a uni-dimensional physical entity that should respond to obliteration or division of nerve pathways (Seymour *et al*, 2005). As Seymour *et al* explain, once the concerns about morphine had been disproved, largely by the efforts of hospice founder, Cicely Saunders, and the anaesthetist and pain specialist, John Bonica, use of morphine increased dramatically and the technological interventions waned. In addition, Twycross (2001:29) states that neurolytic (destructive) procedures decreased since the advent of spinal analgesia and infiltration of local nerve roots with anaesthetic and corticosteroid, although these are not practical when pain extensively involves the hemithorax due to the risk of causing respiratory complications.

A retrospective review of 53 patients with mesothelioma who had undergone percutaneous cervical cordotomy between 1985 and 1998 revealed that the median daily dose of morphine was 100mg pre-cordotomy and 20mg after the procedure; 20 (38%) patients were able to discontinue morphine, 43 patients (83%) were able to halve the dose but 18 patients (34%) subsequently required increased doses (Jackson *et al*, 1999). Although the authors are enthusiastic about the role of cordotomy in mesothelioma, the figures demonstrate that prolonged benefit, (at a median post-procedure interval of 9 weeks), defined as opioid dose reduction or cessation, applied to 25 patients (47%) and that 11% experienced significant side effects in the form of 'mild weakness' and 'troublesome dysaesthesia'. Previous studies have demonstrated 6% mortality at one week post-procedure but Jackson *et al*'s (1999) study reported 6 deaths (11%) within 2 weeks of the procedure. However, the authors report that selection criteria have subsequently been adjusted to exclude patients very close to death. Most patients were taking morphine and non-steroidal anti-inflammatory medication but the full range of analgesics specifically for neuropathic pain had not been employed in this sample; the authors refer to

adjuvant analgesics but state that, in their experience they are 'not very effective'. Therefore Jackson *et al*'s study does not compare cordotomy with the efficacy of commonly used adjuvant medications for neuropathic pain such as corticosteroids; calcium channel blocking agents; antidepressants and NMDA-receptor-channel blockers (Twycross 2001:51-56). The authors of this cordotomy study, specialists from respiratory medicine and a pain department, did not include a palliative medicine physician

However Price *et al* (2003) reported that the 6% (unqualified) mortality in the earlier study could be attributed to the patients' diagnosis of advanced lung cancer. He investigated 37 patients who had undergone percutaneous cervical cordotomy, (32 had mesothelioma), and concluded that respiratory function was not adversely affected, apart from transient nocturnal hypoxia immediately post-procedure.

Of particular note is the finding from Jackson *et al*'s study (1999) that 34% of patients who initially benefited from cordotomy subsequently required more morphine. Referred pain, affecting sites distant from the original pain, was found in 11% of patients who had undergone cordotomy; Nagaro *et al* (1993) proposed that cordotomy removes inhibition of subsidiary neural pathways outside the lateral spinothalamic tracts.

A review of specialist pain management in 259 patients in Italy between 1983 and 2000 found a dramatic decrease in the use of cordotomy from 22 cases in 1983 to none in 2000. (De Conno *et al*, 2003). This was attributed to growing appreciation that a unilateral, localised source of pain was unusual in malignancy, better use of adjuvant analgesia and concerns about 'severe complications' including 'motor, bladder and respiratory function impairment'.

Bruera (2003) in a review of treatments for cancer pain discusses neurosurgical ablative procedures and concludes that '*all these interventions are complex and expensive and their role is not currently supported by large randomised controlled trials; however, they can be useful in selected intractable cases*'. Thus it would appear that the role of cordotomy, an invasive procedure with potentially distressing or severe complications and no guarantee of prolonged symptom control, has yet to be established in mesothelioma, in contrast to the

conclusion of Jackson *et al's* (1999) study which states that the procedure should be considered 'as soon as pain due to chest wall invasion is suspected'.

However, recent work could lead to a reversal of the trend away from interventional analgesia. There are suggestions that spinal analgesia, compared with non-invasive routes of opioid administration, may give a survival advantage in cancer due to the lower doses required. This links to work suggesting that long-term morphine impairs the immune response and also suggestions around inadvertent neurotoxicity with oral morphine due to inexperienced management (Sacerdote *et al*, 2000; Daeninck and Bruera, 1999). If a survival benefit of spinal analgesia in cancer were to be established, it would have substantial implications for practice. However, the holistic management of pain as a bio-psychosocial problem, and not simply as a nerve conduction issue, is essential, regardless of technological advances. Chapman *et al* (2005) support this in mesothelioma, recognising the severe psychological and physical disease burden.

The medical records data, relating to patients who died between 1998 and 2001, suggest that at that time, pain management was sub-optimal: there was little use of the full range of opioids; morphine doses in general were low; and referrals to palliative medicine and specialist pain management services were very frequently late. Hawley *et al* (2004:23-6) found a similar problem with inadequate and late referral to palliative care in her study of mesothelioma in Australia and, in common with a UK study (Hanratty, 2006), she also concluded that under-referral is associated with professionals' knowledge of specialist palliative care and their belief that palliative care is synonymous with terminal care. The failure to access specialist advice at an early stage from experts in symptom control represents serious disadvantage to these patients.

Society equates cancer with pain even though modern approaches to pain management should ensure that most cancer pain can be relieved. However the reality is somewhat different as accounts of cancer narratives illustrate (Winslow *et al*, 2005). As illustrated through the accounts of patients and relatives, there are continuing problems in hospital settings in providing adequate analgesia for cancer pain and issues around training and supervision of junior doctors in palliative care (Winslow *et al*, 2005). In addition, the



investigation of Harold Shipman, notorious GP and mass murderer, has paradoxically (anecdotally) led to such nervousness ('opiophobia') amongst some doctors concerning the prescription of opioids that obtaining powerful analgesia may now be more difficult than previously (Small Practices Association, 2006). GPs worry about tighter regulations around the handling and prescription of controlled drugs to the extent that some no longer carry these medications and it is now recommended practice that patients or family members collecting opioid analgesia from a pharmacy may now be asked to provide identification if they are not known to the pharmacist (Department of Health, 2006b).

### *Other symptoms*

Interestingly, although acknowledged as one of the most common lung cancer symptoms (Cooley, 2000), fatigue was not emphasised by the patients with mesothelioma nor mentioned in many of the medical records. This may be because many of the patients' activities were limited by breathlessness or, alternatively, because fatigue was seen as inevitable, given a cancer diagnosis that in any case was not remediable. Perhaps a hierarchy of symptoms operates in healthcare, with pain at the top, and yet other symptoms may be most burdensome to the patient and family. This reveals the importance of patient-centred care in which the patient's concerns create the priorities for attention from the healthcare team. Sweating was a significant problem for several families and was reported in 18% of the medical records – this is likely to be an underestimate. Unfortunately this symptom is not included in the EORTC QLQ-C30 which is one of the two validated health-related quality-of-life instruments in mesothelioma<sup>92</sup> (Nowak *et al*, 2004) - perhaps it should be?

### *The burden of medical interventions*

All four parts of the study echoed previous reports that reaching diagnosis in mesothelioma can be difficult and is often delayed (BTS, 2001; Hawley *et al*, 2004:22-26). Repeated pleural aspiration and pleurodesis for recurrent effusions represent a particularly heavy investigation and treatment burden because the procedures are invasive, painful and, in the case of pleural aspiration, performed when patients are highly symptomatic and distressed.

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<sup>92</sup> The other is the Lung Cancer Symptom Scale (Hollen *et al*, 2004)

Although some of the patients tolerated these invasive procedures reasonably well, perhaps because they were an understandable physical solution to a distressing symptom, spouses found them hard to witness. As shown in the later section on disease trajectory, the lives of patients and their families were disrupted by unpredictable emergency admissions usually related to effusions or, less commonly, to pain. This illustrates one of the disease management challenges: what needs to be done to pre-empt some of these crises?

Aspiration of pleural effusions, also known as thoracentesis, was essential for symptom relief and, in some cases, the diagnosis was confirmed by analysis of the pleural fluid. Complications, experiences of which were described by some of the patients at interview, have been extensively reported and include pain (15 – 28%), pneumothorax (up to 30%), shortness of breath, cough (9-24%) and vaso-vagal reaction (2-4%). These complications can be significantly reduced if the procedure is performed by experienced interventional radiologists under ultrasound guidance but this is not common in the UK (Jones *et al*, 2003). The recent introduction of medical thoracoscopy in which a physician conducts the procedure using a flexible thoracoscope may improve both time to diagnosis and access to effective pleurodesis if early results are confirmed and if the service is then expanded (Munaavar, 2006).

The interview data illustrates how patients balance the pros and cons of investigative and therapeutic procedures using a range of elements that are not limited to disease factors but encompass practical and social issues too. It would appear that healthcare professionals are mostly unaware of these wider considerations that affect patients' decision-making around interventions.

The mixed views of patients with regard to pleurodesis, after the event, related to whether it was successful or not; whether the procedure was performed on the ward or in a thoracic surgery unit; the perceived expertise of the doctor; and, particularly with regard to Barrow patients, the distance of the surgical unit from their home. Distance to tertiary centres may also influence doctors' referral decisions. A further concern is the late referral for pleurodesis that particularly affected patients from Barrow and the related lower success rate as predictable from the literature: this is because as disease advances the involvement of the

visceral pleura causes 'trapped lung' which cannot expand (Martin-Ucar and Waller, 2006:255-6). These issues are discussed further in 7.4.

### 7.3.2 The psychosocial experience

#### *Finding out about mesothelioma*

Prior awareness of mesothelioma, as described mainly by bereaved relatives, was usually associated with anxiety due to family- or community-acquired information that framed mesothelioma as a dreadful disease, with distressing stories of 'drowning in fluid', 'suffocating to death' and 'agonising pain'. This contrasts with Thomas *et al's* study (2001), which revealed that prior suspicion of cancer sometimes helped prepare patients and relatives for the diagnosis. Perhaps in the public 'folklore' of mesothelioma the diagnosis is associated with such certain terrifying features that patients perceive it as an utterly hopeless death sentence, in contrast to other more common cancers that are increasingly amenable to treatment. This conflicts with the health education message that proposes the need for early diagnosis of cancer in order to achieve a cure. Some patients and relatives may have heard reports of the chemotherapy agent for mesothelioma, pemetrexed, which has recently been reported as an effective, albeit not curative, treatment in terms of an increase in median survival time of 2.8 months and improved symptom control (Vogelzang *et al*, 2003). However, the final decision concerning NHS funding for this treatment will not be announced for some months (NICE, 2007).

Regardless of any prior awareness the diagnosis came as a shock to most people (p147-9). As reported in earlier studies, alongside the content of the disclosure of the diagnosis, the quality of the communication, in terms of the doctor's manner and language, was recalled vividly by patients and relatives (Thomas C *et al*, 2001:87-9; Frank, 1991:27, 50-51, 56; MacDonald, 2004:65-9). The diagnosis of terminal disease is, by definition, a once in a lifetime occurrence, and becomes a personal horror story that is seared into memory; this mirrors the detailed and persisting recollection of bad news received in other severely shocking circumstances such as learning that a child has been murdered (Riches and Dawson, 1998) or that war has been declared.

Patients and, to a greater extent, bereaved relatives, expressed their recollection of the explanation of the diagnosis as a hopeless message –no treatment, no cure, no planned care, sometimes no referral on to support services. The devastating news was frequently accompanied by details of the entitlement to specific Industrial Injury Disablement Benefits and encouragement to engage a solicitor in order to pursue a claim for civil compensation. As many of the patients, bereaved relatives and nursing staff revealed, the combination of the bad news of the diagnosis with financial claims advice was felt to be inappropriate and too much information at one time; for many families it just added to the overall distress. The best time to introduce information about financial claims is not clear but it is evident from this study that, in most cases, it should not occur at disclosure of diagnosis. Perhaps one reason why this practice is so widespread is that doctors may regard financial compensation as the single positive message amongst the otherwise bad news; however patients and their relatives feel otherwise. Alternatively it may be that financial information is a distraction, or even a ‘blocking technique’, employed by doctors in order to reduce the focus on the fatal disease and diminish their own anxiety amidst the emotionally-charged conversation about incurable disease and the lack of effective treatments (Macdonald 2004:67; Brennan, 2004: 311-2).

Fostering hope in this situation was obviously challenging for healthcare professionals and, in spite of the requirement that all healthcare staff involved in breaking bad news should receive training in communication skills, many reported in interviews that they felt inadequate for the difficult task. It was apparent that much more than communication skills training was necessary in these situations and this raises fundamental issues concerning the nature of the doctor-patient relationship. Some doctors were clearly comfortable in expressing to me their own emotional distress around disclosing the diagnosis of mesothelioma, exhibited concern, and were able to develop a closer relationship with some of the patients and their families than usual. Similarly, some patients and relatives reported much appreciation of close relationships with their doctors. This echoed Buckley and Herth’s (2004) study that demonstrated how good doctor-patient relationships assist in fostering hope in terminal illness; indeed Balint (1957) famously conceptualised ‘the doctor as the

drug'. It could be postulated that positive relationships contributed to meaningfulness and helped to restore sense of self in some patients.

In the situation of terminal illness, the life-world of the ill person (and their main carer) contracts and becomes inwardly focused; the ill person may become extremely sensitive to the nature of their relationship with healthcare professionals. Palliative care professionals in particular may regard their role as extending beyond the purely professional to include a deeper interpersonal connection. However, Sandman (2005:6) points out that this must be a voluntary decision of the individual. It is well recognised that there may be a personal cost in repeatedly extending the usual boundaries of the doctor- or nurse-patient relationship in terms of emotional exhaustion, burn out and impact on personal life (Brennan, 2004: 365-389).

Reactions to the diagnosis differed between patients and relatives. The patients seemed to take a variable time to get over the shock of the diagnosis but subsequently they exhibited a very similar pattern: they all reported wanting to try to maintain normality and make the best of the situation for as long as possible, relying heavily on their spouse for support within their own homes. Most patients appeared to accept their situation with a mixture of stoicism and fatalism. Bereaved relatives, on the other hand, recalled the diagnosis as shocking and distressing, were more questioning, often explored a variety of information sources and rapidly assumed new responsibilities and roles as necessary to support the situation. This reflects the 'seeking behaviour' described in relatives of newly diagnosed stroke patients (Brereton and Nolan, 2002) in which they made efforts to find out about the condition and what they needed to know and do in order to care for the person at home. However, the essential difference is that in stroke there is the hope of some, if not total, recovery. The different reactions to the diagnosis as reported here concerning patients and bereaved relatives must be seen in the light of the different methodologies used: the patients were interviewed whilst suffering from mesothelioma and facing impending death: their accounts reflected the way in which they were coping with their situation. On the other hand, the bereaved relatives were recalling their experiences in retrospect and through the lens of loss, and many were still grieving; these factors will have influenced their accounts.

Care pathways are increasingly used to reduce variations in care. However, as is obvious from the many unanswered questions regarding mesothelioma, the evidence base is not sufficient to enable robust guidance to be produced at this stage (BTS, 2001). The UK system contrasts markedly with the US, where first-line treatment (for the 80% of the population covered by health insurance) now includes chemotherapy with pemetrexed. However this has to be seen in the context of two very different healthcare systems with differing funding arrangements. Any assessment of the NHS costs of pemetrexed should consider the low uptake of chemotherapy in mesothelioma: a recent study has shown that only 36% of patients are suitable for chemotherapy and, of these, less than half opted for treatment i.e. 17% of the total number of patients (Chapman *et al*, 2006). The trial that compares active symptom control in mesothelioma either alone or with chemotherapy is not expected to report until autumn, 2007 (Muers *et al*, 2004). Although even the best results from chemotherapy are modest in terms of improved survival and response rates, the decision not to fund pemetrexed, at an estimated cost of £9.6k per patient (Regional Drug and Therapeutics Centre, Newcastle, 2006) adds to the perceived neglect and disenfranchisement of people with mesothelioma. This contrasts with the successful highly-publicised public campaign that overturned the NICE decision not to fund the breast cancer drug, Herceptin at an annual cost of around £21k per patient (Netdoctor, 2006).

However, if truly patient-centred care were considered, empowering those patients who wished to understand their illness, thus potentially enhancing their ability to cope with its impact, would be promoted. In some conditions this is being undertaken in the Expert Patient Programme (Department of Health, 2001): this scheme enables patients with chronic disease to learn as much as possible about their illness and self-help measures, and to use this knowledge to educate and support others with the same condition. Sadly, this is not likely to be feasible in mesothelioma for many patients, given the median survival in this study of 294 days, although this may change if new chemotherapy agents improve survival in future. However the information needs of families with regard to managing symptoms do not appear to be addressed and this could represent an intervention to be evaluated in the future (Chapter 8). Cancer charities have a long history of providing patients and relatives with information

and mesothelioma is no exception; Mesothelioma UK provides information for patients on its website, [www.mesothelioma.uk.org.uk](http://www.mesothelioma.uk.org.uk) and patient education was the theme for the 2006 national conference of the Mesothelioma Applied Research Foundation in Chicago (MARF, 2006).

### *The crisis of terminal illness*

Many respected authors have described the impact of terminal illness as a major identity crisis involving a sudden overturning of a lifetime's assumptions, hopes, and expectations with accompanying loss of self (Macnamara, 2001:35-7; Bury, 1982; Brennan, 2004:21-33). This ultimate existential personal challenge therefore requires a reconceptualisation or renegotiation of notions of self (Mathieson and Stam, 1995). Brennan (2004:12) explains the process of adjusting to a cancer diagnosis as the move from initial turmoil to the establishment of a more coherent 'mental map' that reflects the new life world. He also points out features of post traumatic stress disorder with denial or avoidance strategies to minimise the initial impact followed by intrusive thoughts or flashbacks and increased arousal (Brennan 2004: 16). Similar characteristics were demonstrated in the interviews with patients but more noticeably in the bereaved relatives' accounts.

Loss of self is connected to the perceived stigma associated with manifestations of illness (Goffman, 1963:3). In mesothelioma many factors contribute to stigma: notions of contagion associated with asbestos exposure; possibly self-blame for being careless with asbestos (even if unaware of the dangers at the time); the generic stigma attached to any cancer diagnosis and the particular stigma by association with lung cancer; (Chapple *et al*, 2004), the visibility and social embarrassment of breathlessness and associated loss of agency; the unpredictable disruptions caused by pleural effusions; the severe bodily changes; the lack of effective treatments; the connection with financial claims involving legal processes; and, in some cases, unsatisfactory relationships with some healthcare professionals.

Some of these issues are gendered: the majority of the male patients had worked in traditional, physically demanding, occupations in male-dominated industries where their physique was their capital and they also fulfilled a 'manly' role at home by undertaking the more physically-demanding tasks. The loss of

gendered identity, as affecting sexual function, has been reported with regard to hormone treatments in prostate cancer that cause impotence but, in mesothelioma, the emasculation, hinted at by two patients in interview, appears to be more to do with loss of general physical function and change in body image resulting in loss of traditional masculine role. Inevitably this alters the presentation of self and social interactions (although one male patient did report a sexual problem) (Brennan, 2004:127-130; Moynihan, 1998). However, loss of a traditionally gendered role also affected the female patients as they became too ill to undertake their normal domestic tasks. Costain Schou and Hewison (1999:85-92) describe this in terms of the impact of the illness on the patients' personal calendar as well as their role.

The rapid progression of mesothelioma means that the illness usually impacts rapidly on many of these areas and, in contrast to more slowly progressive conditions, does not allow any time for adjustment. Charmaz (1983) reports how these conditions can impose 'an all-consuming retreat into illness' and may lead to 'an encompassing concern with self'. To some extent this could explain relatives' reports that some patients became very demanding in advanced illness, seemingly inconsiderate of other demands on the carers' time.

Another perspective on dealing with the challenge of a terminal illness derives from narrative and biographical studies and emphasises the need to regain a sense of coherence when life is disrupted by illness; this may be achieved by re-establishing a legitimate life story, a narrative that encompasses the curtailment of hopes and expectations and indeed life itself, in other words, by revising the way in which life has previously been understood (Frank 1991:60; Kellehear, 1996:157). Narrative accounts do not necessarily report literal truth but they do reveal how people experienced their individual situations. In these accounts the narrative eventually becomes the experience, evolving meaning with the telling and retelling, and also impacts upon the listener and becomes the understanding and meaning of the illness for them too (Kleinman, 1985:49-50). Biographical approaches, in which patients are enabled to produce a written 'life storybook' have been shown to enhance family relationships and improve staff attitudes to older people (Clarke *et al*, 2003). Similarly, Frank, (1991:59-68), a sociologist who has experienced cancer and a heart attack, illuminates how suffering due to illness requires a narrative that attempts to



reform the disrupted 'life map' and loss of self caused by illness. Cassell (2004: 106, 282-3) contrasts reductionist medical case histories with the broader patients' illness stories and emphasises the value of listening to patients' illness narratives in order to understand how they experience their conditions and how to direct any interventions in terminal illness towards the patients' own goals rather than at the disease. Similarly, Kleinman (1985:121-36) illustrates that an understanding of patients' illness meanings can lead to more effective care. These authors make a strong case for the value of illness narratives in improving care of patients and reducing their suffering.

It has been argued that patients with terminal illness need to find a new meaning within the unfamiliar context of facing death, and in order to do this there needs to be some balance between despair and hope: life without hope is meaningless (Buckley and Herth, 2004). There is an increasing body of literature illuminating the importance of helping patients to regain a sense of hope even in the most dire circumstances; much recent work relates to people suffering from AIDS/HIV (Kylma, 2005). In the accounts of patients with mesothelioma many features combined to diminish hope: the prior knowledge of mesothelioma as a terrifying fatal disease, sometimes within the patient's family, the perceived (or actual) communication from doctors that 'nothing can be done', uncontrolled breathlessness and/or pain, the loss of agency and control compounded by rapid bodily deterioration, the erratic unpredictable disease trajectory, notions of stigma and contagion as well as the unfamiliar and worrying involvement in claiming State benefits and litigation. The bereaved relatives' accounts also reflected hopelessness, often in combination with helplessness, leaving them feeling inadequate and impotent. Hopelessness, helplessness and despair, have been shown to be inter-related and predictors for depression and suicide (Breitbart and Krivo, 1998:542-3).

### *The meaning of the 'coping narrative'*

The patients with mesothelioma experienced rapidly deteriorating health, unpredictable emergency admissions due to recurrent effusions, and multiple invasive medical interventions that all impacted upon their normal activities. McNamara (2001:35-7) explains that patients seek to understand their new 'illness identity' in terms of the effects of the bodily changes and that deterioration reinforces their gradual loss of self and awareness of impending

death. Similarly, Cassell (2004:33-6) describes how uncertainty around unpredictable symptoms and their management leads to loss of control which compounds the identity crisis of terminal illness; previously competent mature adult patients and their close relatives become disabled by loss of agency. Patients approaching death are confronted with multiple losses and fears, often the fear relates to the process of dying more than the loss of life. Loss of identity, independence, and the expected future life, commonly feature in the concerns of patients close to death. Fears tend to focus on separation from loved ones and the familiar life, uncontrolled symptoms, being a burden, as well as the dying process (Brennan, 2004: 268-270). As Charmaz (1983) points out 'the language of suffering is a language of loss'. In spite of these factors, a striking feature of the patients' accounts was their determination to assure me that they were coping; I have called this 'the coping narrative' and will now elaborate on it.

The patients' emphasis on being in control and coping may have been one way of maintaining a sense of coherence at a time of turmoil. Terminal illness destroys prior notions of identity and purpose; in this chaotic situation it may be important to retain some degree of control wherever possible and that may be easier to maintain in conversations with a stranger than with family and friends Moynihan (in Brennan, 2004:162-4) describes gender differences in coping strategies in terminal disease: she describes men with prostate cancer 'coping with silence'. This may again relate to characteristics of the men from this generation and socio-demographic group in whom displays of emotion are regarded as unmanly

In his book, *The Wounded Storyteller* (1995), Frank categorises three typical illness narratives: the restitution narrative that seeks a positive outcome, the raw uncontrolled chaos narrative that is disrupted with no hope of an acceptable outcome - 'sucked into the undertow of illness', and the quest narrative in which illness is experienced as a journey or transformation. The 'coping narrative' identified in this study can be interpreted in a variety of ways, illustrating the complexities of the lived world experience that are revealed by qualitative enquiry (Kvale 1996:5; Kleinman, 1988:49-50). Although it may seem tautologous to describe the 'coping narrative' as a coping strategy, this is nonetheless what the study appeared to reveal.

It seemed that 'coping' was a positive choice and was essentially a vital component of a restitution narrative that sought to contain the catastrophe of terminal illness (Frank, 1995:77-84). Coping is associated with traditional masculinity in British culture and is part of the metaphorical 'stiff upper lip' that typifies the male response to crisis as stoical, competent, unemotional, and dependable. In contrast, 'not coping' is seen as a dereliction of masculinity. Patients, and their spouses, referred to themselves as 'coping' even when circumstances were obviously difficult. This can be compared to accounts from men with advanced prostate cancer who expressed themselves as usually being well, in spite of their terminal illness, and revealed that their sense of 'wellness' depended more on *not* being acutely ill or symptomatic than any medical definition of being well in terms of absence of disease (Lindqvist et al, 2006). The patients with mesothelioma were mostly symptomatic and were telling their illness stories, thus they could not represent themselves as being 'well' but perhaps their perception of, or desire to be seen as, 'coping' was an alternative positive stance that had 'not coping' as its counterpoint. The patients' concerns that were expressed about 'not coping' mainly related to uncontrolled physical symptoms rather than emotions, although there was a hint of fear of losing emotional control in one man who wondered how he would cope when things got worse, remembering how his father had suffered when dying from mesothelioma. Perhaps related to the coping narrative, two male patients with mesothelioma did describe making efforts to attempt to stay 'healthy', and this contradicts the traditional Men's Health discourse that presents men as doing little or nothing to protect their health (Gough, 2006). These efforts may also represent an element of regaining control over a chaotic situation – another version of the restitution narrative.

'Coping' can be seen as a way of regaining some mastery over the disruption of life as it was and as it had been expected to continue, note the gendering of the term 'mastery'. Even when a medical or social assessment of coping would have concluded that assistance was required, the patients' responses reflected their (unspoken) need to keep up the 'pretence' (or performance in Goffman's (1959:44-59) terms) within the family, or, more particularly, outside the family, that they are in control of the situation. This highlights one of the alarms raised by Lindqvist *et al's* (2006) study which illustrated that, by focussing on the

*physical problems* in advanced disease, healthcare professionals may actually interfere with patients' strategies to find meaning and hope in their situation and to regain some degree of control. There are also problems with medical models of coping that categorise the ways in which people cope with, or adjust to, terminal illness: applying singular labels to these issues, such as 'emotion-based coping' or 'fighting spirit', diminishes the complexity and individuality of each patient's own response and does not acknowledge that coping is not a fixed entity and varies with time and situation (Brennan, 2004:23)

The perception of coping may be one way of fostering hope when facing death. The 'resigned acceptance' reported in earlier work concerning the psychological reactions to mesothelioma could be seen as reflecting hopelessness (Lebovits *et al*, 1983). In attempting to fend off despair, arguably a rational reaction to impending death in a secular society, the development of a coping narrative engenders hope and restores a sense of self. This may be particularly relevant in these patients from traditional families and 'old-fashioned' industries because it supports the traditional masculine hegemony. The interviews also revealed that although most patients were presenting themselves in the interviews as coping, there were brief acknowledgements that sometimes the 'mask slipped' and emotional distress could not be held back. The exception was the 'devastated' man who was too ill to speak: in his case his physical condition was so weakened that with only days to live he had lost all agency; in this situation his loss of self was 'non-negotiable' (Lawton, 2000:117) and, without hope, he exhibited complete despair. Whereas the patients' accounts to me focussed on their ability to cope, the bereaved relatives told a different and more intimate story of severe distress, hidden behind closed doors and contained within the family, usually between husband and wife. The findings mirror many reports of living with terminal illness in which patients oscillate between hope and despair, often referred to as the 'emotional roller coaster' but in mesothelioma, survival time is shorter than for many common cancers and the adjustment process may be impaired by rapid physical decline, punctuated by crises, that has an additional negative impact on hope.

The coping narrative links to two other perspectives on how patients cope with terminal illness. Folkman and Lazarus (1988) defined two categories of coping: emotion-based and problem-based coping. These categories tended to be

gendered, with men more likely to exhibit problem-based coping than women. Morse (2001) distinguished between suffering experienced as enduring and alternatively as emotional suffering. It would seem that the narrative of coping, as expressed by the patients with mesothelioma, has features in common with both problem-based coping as opposed to emotion-based coping and enduring as opposed to emotional suffering. This should not come as a surprise given the personal characteristics of the patients involved in this study and reflecting the types of lives they had lived – they approached dying in the way that they had lived. However, two patients were exceptional in that they made practical plans to assist their spouse in bereavement and these patients were both women. This contradicts the Folkman and Lazarus (1988) theories of coping in which women tended to exhibit emotion-based coping and men, problem-based coping. In this study the women patients were the practical ones when it came to planning ahead. Perhaps this can be seen as a demonstration of reciprocal caring in which these wives were thinking more about their husbands, and how they would cope when alone, than themselves.

Thus coping may be seen as an active and unemotional means of 'enduring' an illness rather than the passive and emotional 'suffering from' it (Morse, 2001). Morse illustrates how *enduring* focuses attention on the present and this has obvious benefit in mesothelioma if it allows patients to 'live for the day' and avoid the future confrontation with impending death and the past issues to do with blame and causation. Emotional suffering on the other hand reveals the reality of all that is lost when life is ending. It appears to demonstrate hopelessness and helplessness, and the visible nature of emotional suffering impacts on those close to the patient. Unemotional coping may have been one way in which to handle anger and other negative emotions. Previous studies of patients with mesothelioma revealed anger as a common reaction and related to the culpability of negligent employers who failed to implement asbestos safety procedures (Lebovits *et al*, 1981 and 1983). Frank (1991:112), writing about his personal experience of cancer, criticises the notion of the typically passive cancer patients and explains that patients with cancer cannot risk being angry as it could alienate healthcare staff and thus potentially impact on their treatment; he states that patients with cancer tend to express anger when they feel they have nothing left to lose. This resonates with the anger in the focus groups with bereaved relatives: they certainly felt they had nothing left to lose

(Boxes 5.7 and 5.8). As Hill *et al* (2003) report, patients with lung cancer have many concerns about the burden of the illness on their family, this is another reason why patients attempt to reduce the manifestation of emotional suffering. Many of the bereaved relatives' accounts reflected pride in the way that their loved ones had borne their illness with great fortitude, reflecting the metaphor of the 'heroic' patient in their battle with terminal disease in which perseverance and stoicism, rather than physical superiority, are the elements of mythical heroism - another restitution narrative that reflected 'rising to the challenge'. (Frank, 1995:117-9).

The coping narrative may have been a useful and effective device to block enquiry that might follow an admission of problems in order to prevent emotional distress for the patient and/or their spouse. On the other hand, this also let me, as the researcher, 'off the hook' and led me away from enquiring into sensitive areas, thus fending off potential distress for me too – this (subconscious) apparent collusion was not noticed during the interviews but grew from my later considerations and interpretation of the data. Perhaps, if serial interviews had been conducted, further delving into 'not coping' may have been possible but it would have been essential to be sensitive to the ethical issues inherent in any interaction that could impair patients' strategies for dealing with their illness.

However, I reach a different conclusion to Frank (1995:94) in consideration of the problems he envisages with restitution narratives when the disease is not amenable to treatment: Frank states that in such circumstances 'other stories have to be prepared or the narrative wreckage will be real'. My interpretation from this study is that it *is* possible to develop restitution narratives in the face of terminal illness in which the eventual positive outcome is a good death, or perhaps more accurately 'good dying', rather than recovery from ill-health. This is articulated in the 'coping narrative' as described above, in which the elements can be summarised as: coping as a positive choice, coping as mastery, coping as fostering hope, coping as enduring, and coping as a blocking tactic.

Finally, it has to be remembered that the patients who were interviewed had volunteered for the study. In some cases they revealed an altruistic motive for participating in the interviews and this would also support the notion of a

restitution narrative, perhaps in terms of a 'manifesto' (Frank, 1995:120-1). However, given the multiple concerns that patients with mesothelioma are faced with and the link between severe psychological distress, symptom burden and lung cancer (Zabora *et al*, 2001), as well as the severe emotional distress exhibited in the focus groups with bereaved relatives, it must be considered that patients with mesothelioma inevitably face a severe psychosocial burden. Although it is beyond the scope of this study, it must be considered whether another category described by Frank (1995:97-114), that of the 'chaos or unspeakable narrative', might apply to some of the non-participants and that the 'coping narrative' may be the most acceptable alternative for some patients in contrast to revealing the actual horror of the situation.

## **7.4 The disease burden, trajectory and service usage**

Disease burden is a term used in epidemiology to describe the loss of expected years of life due to a particular disease and relates to the impact on productivity and economic contribution that individuals make to society (WHO, 2007). In this chapter I will use the term in a less technical sense: disease burden in this context relates to symptom burden; the impact of medical investigations and interventions; the psychological and social toll of the disease; the progression of the disease, as well as the untimely, potentially preventable, and unanticipated death. In view of their interconnectedness, this subchapter considers disease burden, trajectory and service usage together. This study did not aim to conduct statistical or economic analysis of healthcare services utilised by patients with mesothelioma but, as shown in Chapter 3, was able to determine the figures for hospital admissions, GP consultations and outpatient attendances in the last year of life from the medical records sample.

The severity of the symptoms and the disease impact, discussed earlier are in line with Nowak *et al*'s (2004) study: patients with mesothelioma completing the EORTC QLQ-C30 quality of life questionnaire revealed higher scores in the areas of pain, social role and functioning, and equal scores for breathlessness, when compared with patients who had lung cancer.

All the data sources demonstrate that patients had a considerable number of encounters with healthcare staff due to the specific symptom burden, the

difficulty in achieving a diagnosis and the particular problems around management of recurrent pleural effusions as well as for terminal care in most cases. Presumably the fact that 'best practice' has not been determined for mesothelioma accounts to some extent for the variation in management, both between individual patients, and across the three study sites. However, even when guidelines are available, such as the BTS (Antunes *et al*, 2003) guidance on the management of pleural effusions, (Box 1.2) and also the BTS (2001) statement on mesothelioma that suggests early referral to palliative care, they do not appear to be implemented – a situation by no means unique to mesothelioma. A Mesothelioma Framework (Department of Health, 2007) has just been launched by the Lung Cancer and Mesothelioma Advisory Group of the Department of Health – this provides guidance to Trusts, Cancer Networks and purchasers on 'the optimum organisation of services for patients' but is not an evidence-based clinical guideline (Peake, 2007). The BTS Statement on Mesothelioma (2001) is also currently being updated. However, given the dearth of new research in mesothelioma, and the historical privileging of oncological and technical approaches above palliative care, it is to be hoped that these opportunities to promote the pivotal role of palliative care will not be missed.

### *Presentation and referral*

The most likely reason for the relatively early presentation of patients with mesothelioma to their GP is the highly-symptomatic onset due to pleural effusion and/or pain in most cases, although it is not possible to ascertain from this study to what extent insidious symptoms may have been present prior to the acute presentation and for how long. The medical records survey revealed that the median time from recorded symptom onset to presentation to GP was 17 days, (mean 43 days, range: same day -212 days). Studies in lung cancer tend to show longer intervals: for example, mean 138 days for non-specific symptoms and 72 and 79 days for dyspnoea and cough respectively (Thompson and Hetzel, 1997) and between 21 and 93 days in 'almost two thirds of patients who attended their GP because of chest symptoms' (Kirshnasamy and Wilkie, 1999: 52). The longest delays to presentation in this study were attributable to patients having complicating co-morbidities that obscured the significance of new symptoms. Contrastingly, Hawley' *et al*'s (2004) interview study with 9 patients with mesothelioma in Australia found 'considerable' (but



un-quantified) delays between symptom onset and presentation to hospital similar to lung cancer but these different patterns may reflect different funding of healthcare and different access to services, for example due to rurality.

From the medical records survey, and confirmed by the interviews with patients, GPs tended to act quickly when a patient with breathlessness and/or chest pain presented to them, with the result that most patients were seen in hospital within a month of onset of symptoms. However the median interval between symptom onset and presentation at hospital varied from 30 days in Barrow and Leeds, to 80 days in Doncaster, giving an overall median interval of 36 days; this difference across the sites is unexplained. Examination of the notes of patients with the longest intervals revealed that they tended to have complicating co-morbidities to which new or deteriorating symptoms were attributed initially, but this was not more common in the medical records from Doncaster patients. This situation of relatively rapid access to hospital services reflects the situation in three areas where mesothelioma is relatively common and therefore doctors might be expected to have a high index of suspicion for the diagnosis when presented with typical symptoms. However, it is more likely that the dramatic presentations of rapidly developing breathlessness and/or pain prompt the early referral to hospital. In lung cancer it appears that patients' decisions to see their GPs relate to the number of new symptoms rather than severity of symptoms (Krishnasamy and Wilkie, 1999: 52). In this mesothelioma study and the lung cancer study, (Krishnasamy and Wilkie, 1999:55) similar percentages (15% and 16% respectively) of patients accessed hospital services without GP referral.

### *Confirming the diagnosis*

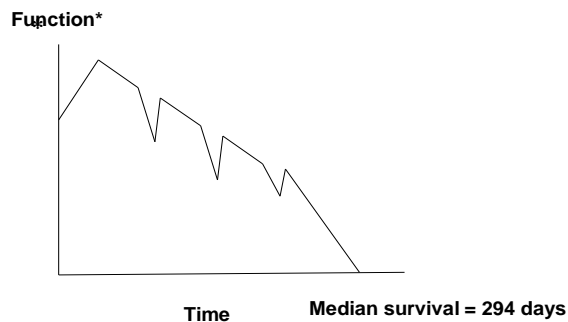
Delay in reaching diagnosis is common in mesothelioma (BTS 2001) and in this study confirming the diagnosis took over three times as long as in lung cancer. In lung cancer, 43% of patients received the diagnosis within 2 weeks of having a chest x-ray in line with national guidance (Krishnasamy and Wilkie, 1999:55; BTS, 1996). In the same study, the longest delay from hospital presentation to diagnosis was 8 months and related to one of the 8 patients with mesothelioma (n=208). The authors comment that delays in diagnosis in lung cancer usually relate to lack of a co-ordinated approach to investigation, usually when patients

have not been referred to a consultant in respiratory medicine initially. This may be relevant to delayed diagnosis in mesothelioma but there are additional technical problems related to obtaining and analysing histological specimens. The medical records' review revealed lack of histological confirmation of mesothelioma in 22% of patients before death (page 108). The challenges of diagnosis reflect the acknowledged problems in histological analysis and differing levels of access to thoracoscopy that affects the yield of biopsies; consequently there are calls for greater access to the relatively new technique of medical thoracoscopy and for a national reference laboratory for mesothelioma (Munaavar, 2006; Haselton, 2001). The median interval of 79 days between hospital presentation and diagnosis represents a long time in limbo for patients and their relatives, and the interviews revealed that this caused great distress for patients and relatives and reduced their confidence in doctors.

### *Disease trajectory*

The course of the disease was one of several emergency presentations due to effusions and brief deteriorations followed by partial improvement after invasive procedures such as thoracoscopy or pleurodesis, usually superimposed on relentless decline. Illustrative representations of the disease trajectory have been produced for cancer, chronic organ failure, and frail elderly or dementia, and they have been useful in drawing attention to the differing ways in which these different diseases tend to progress (Lunney *et al*, 2003). More recently these typical trajectories have been promoted as a useful tool in palliative care, extending beyond cancer diagnoses (Murray *et al*, 2005a and 2005b; Dy and Lynn, 2007). These illustrations, although criticised for being 'unscientific', (if there is no standard measurable variable on the vertical axis), are nevertheless helpful in focussing the attention, in a conceptual sense, of healthcare professionals on proactive care. Trajectories have also challenged researchers to determine how the terminal phase can be identified with the intention of thereby improving patient care, particularly in respect of diseases other than cancer, by 'countering the technological imperative' and signalling the time for referral to palliative care (Murray *et al*, 2005a). However, with the median prognosis in mesothelioma of less than 10 months in this study, the latter consideration should be irrelevant and all patients should be referred at diagnosis (BTS, 2001).

It is possible to use an illustrative representation of the disease trajectory in mesothelioma to show just how different it is compared with most cancers, Figure 7.1. The dip at the start of the graph represents the initial presentation with severe shortness of breath due to a large pleural effusion, with or without pain. After pleural aspiration, symptoms improve for a short time then recur when the effusion recurs. Further deteriorations in symptoms occur with recurring effusions and with pleurodesis or thoracoscopy but the disease usually progresses rapidly and leads to death within the year in 63% of cases, with a median survival of 294 days. There are specific challenges concerning the mesothelioma trajectory: delay in diagnosis shifts the start of the graph; there may be different trajectories relating to differing histological types that are known to impact on prognosis; and there may be subsets reflecting recurrent pleural effusions requiring more interventions or pain at presentation, which is an indicator of worse prognosis.



**Figure 7.1 Disease trajectory in mesothelioma** (\*‘Function’ represents estimated performance status)

In Figure 7.1 above, ‘function’ on the vertical axis is derived from all four data sources whereas in more scientific representations it represents measurements of ability to perform activities of daily living (ADL). A more accurate picture would require a prospective study of serial measurements of function relating to ADL in a statistically valid number of patients with mesothelioma. The ethical and practical challenges of this type of enquiry involving people close to death have resulted in relatives being used as proxies, although concerns around reliability have been described earlier (p71). Nevertheless, further investigation

of the disease trajectory in mesothelioma would appear to be worthwhile and may inform decisions concerning treatment options.

### *Hospital care*

The medical records survey revealed a considerable burden of medical interventions for patients with mesothelioma in the last year of life: median figures demonstrated attendance at 5 outpatient clinics, two or three admissions to hospital, one attendance at a Day Unit and 10 consultations with the GP, 6 of these as home visits. This is in comparison with perhaps one admission of 3 or 4 days for patients with lung cancer (Krishnasamy and Wilkie, 1999:100). In addition, a third of patients with mesothelioma may access hospice facilities, a few see benefits advisors, and the majority also receive care from community nursing teams, lung cancer clinical nurse specialists and Macmillan nurses.

Deficiencies in the organisation of the care of patients with cancer have been highlighted in the Cancer Plan (DH, 2000b) and recent guidance on supportive and palliative care (NICE, 2004) particularly regarding inter-professional communication and coordination of services. The Cancer Plan promoted the development of multi-disciplinary teams that have been shown to improve the co-ordination of care of cancer patients and reduce clinical variation. It has also been demonstrated that for specific cancers, excluding mesothelioma, delays in diagnosis and treatment have been much improved by Cancer Plan performance targets (National Audit Office, 2005). However, this system appears to disadvantage patients with relatively rare cancers such as mesothelioma. Mesothelioma is included in lung cancer MDTs regardless of how much experience the MDT members have concerning this disease. Given the many differences between lung cancer and mesothelioma, such as causation; incidence and distribution; symptoms; difficulty in diagnosis; trajectory; lack of effective treatments and problems with palliation, lung cancer MDTs are not necessarily the ideal place to situate mesothelioma – but in the absence of any better arrangement it is the best compromise. Similarly the patients are usually referred to a Macmillan nurse on a geographical rather than diagnostic basis and again experience of mesothelioma is not taken into account<sup>93</sup>.

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<sup>93</sup> The new Mesothelioma Framework (2007) is designed to address these service provision issues

Ethical dilemmas surround the issue of offering experimental chemotherapy of minimal potential benefit to patients with terminal illness; issues such as the definition of medical futility (Brody, 1997); allocative justice; patient autonomy; paternalism and medical nihilism to name a few. However, Slevin *et al* (1990), caution that healthcare professionals and patients have differing perceptions of risk and acceptability regarding chemotherapy: patients with cancer find 'low benefit' chemotherapy more acceptable than the professionals. This raises questions about the accuracy of patients' understanding of issues such as statistical risk information; opportunity costs; the need to believe that something can be done; and the quality of any information of the benefits of palliative care. O'Neill (2003) describes the ethics of patients' decision-making as having three components: competence, access to adequate information and voluntarism. The importance of the manner in which information is provided and the quantity given is key: O'Neill (2003) stresses the value of allowing the patient to select when and how much information is given, that it may be extended 'in layers', and that patients are assured that they can rescind decisions without penalty. A further complication is the dependent relationship between patient, particularly with life-threatening illness, and doctor, as described by Frank (1991:112); this may lead to the patient attempting to 'best guess' the decision that would meet with their doctor's approval (Harris, 2003).

### *Palliative care*

It is both disappointing and surprising that less than half the patients (49%) were referred to palliative care in the survey of medical records, given the high symptom burden, terminal nature of the disease, and the short median survival. This finding mirrors results from Hawley *et al's* (2004) study of mesothelioma in Australia: they found that delay in referral to palliative care was related to the working definition of palliative care used by the referring doctor: those who believed that palliative care equated to terminal care referred late and, interestingly, this belief appeared to be shared by patients and their relatives. Similarly, Jarrett *et al* (1999) suggested that patients and relatives who hold restricted views of the role of specialist palliative care teams may be disadvantaged by not revealing aspects of need that do not fit with this view and also demonstrated that satisfaction with services is directly related to patients' and relatives' expectations of those services. Late referral was found to limit the

value of the palliative care involvement; early referral allowed trusting patient/nurse relationships to develop; fostered communication around hopes and fears; enabled access to 24 hour support and advice services; improved co-ordination of care, and increased the likelihood of patients dying in the place of choice. Barriers to accessing palliative care included poor co-ordination of services and lack of knowledge of mesothelioma and the Dust Diseases Board<sup>94</sup> (Hawley *et al*, 2004).

UK studies have also demonstrated benefits for patients when they are referred to specialist palliative care services but that there is inequity of access (Hearn and Higginson, 1998; Clark *et al*, 2005:Ch.8). Factors likely to affect access in mesothelioma are the delay in diagnosis; lack of awareness of the steep and erratic trajectory; the 'therapeutic imperative' that privileges active treatments and interventions over the palliative care approach; lack of understanding of the benefits of palliative care, and medical attitudes, including nihilism. In addition, there are resource issues with almost 100 vacant consultant posts in palliative medicine in the UK (Association for Palliative Medicine, 2005), variable provision of palliative care teams across the UK and uneven distribution of hospices and associated services such as Hospice at Home (Wood *et al*, 2004). Nevertheless, the severe symptom burden and specific needs would suggest that input from specialist palliative medicine may be needed as much, if not more, in mesothelioma than in other cancers, as suggested by the BTS (2001)

### *Community care*

Most of the final year of life of patients with cancer is spent at home and GPs and community nurses provide the majority of the healthcare during that time (Thomas *et al*, 2001). This study found similar results: 90% of the time from presentation to death was spent at home but the incidence of mesothelioma is such that even GPs in the highest incidence areas see at most two cases per year and most GPs do not see even one case per year<sup>95</sup>. In contrast, GPs see up to 10 new cases of lung cancer each year, usually between one and five

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<sup>94</sup> The Dust Diseases Board refers to The Workers' Compensation Dust Diseases Board (DDB) of New South Wales: this is a statutory body that provides state financial benefits to people who have developed mesothelioma as a result of occupational exposure to asbestos.

<sup>95</sup> In 25 years as a GP practising 10 miles from Barrow-in-Furness I cared for 4 patients with mesothelioma but the first 2 were so memorable, and their management so challenging, that they prompted this study.

(Krishnasamy and Wilkie, 1999:94). The medical records data showed considerable involvement of most GPs in supporting their patients with mesothelioma in the community, in line with studies confirming that care of patients with terminal illness, although sometimes demanding, is regarded as an important and satisfying GP role (Field, 1998; Borgsteede et al, 2006). The focus group reports confirmed the central role of the District Nurse in maintaining patients in their own homes and supporting the carers (King *et al*, 2006). The role of the Macmillan nurses was less related to direct hands-on care but was related to giving information about the illness, benefits and services. This echoes work by Skilbeck and Payne (2005) that revealed that GPs preferred to work alongside District Nurses than Macmillan nurses with terminally ill patients. Although the paper questioned this preference, it is understandable for two reasons: the GP and District Nurse frequently work closely together in the care of many shared patients and meet regularly, thus developing a strong working relationship over time and the patient and District Nurse may also have a long-established relationship; the GP may only have a few terminally ill patients each year of who approximately a quarter will have cancer and therefore the contact with the Macmillan nurse will be less frequent. The changing role of the Macmillan nurse, moving away from hands-on-care to a more advisory and educational role, has been criticised by Skilbeck and Payne (2005) and this was echoed by one bereaved relative whose expectations of the service had not been met (Box 5.7).

The NHS is currently developing an extensive programme to address the care of patients at end-of-life and this includes three initiatives designed to improve end-of-life care: firstly the Gold Standards Framework (Thomas, 2003; Thomas and DH, 2005) which is a tool that assists GPs in identifying patients in the palliative stage, keeping a register of all palliative patients and adopting a systematic approach to their care; secondly, the Liverpool Integrated Care Pathway (LICP) is a tool that ensures a systematic approach to the care of people with cancer in the last few days of life, and thirdly, the Preferred Place of Care is a document that enables patients to make decisions about where they would like to receive care at the end-of-life (Department of Health, 2004; NHS End of Life Care Programme, 2007; Storey et al, 2003).

The Gold Standards Framework, (GSF), is linked to the Quality and Outcomes Framework that attracts GP remuneration. Alongside a useful website, ([www.goldstandardsframework.org.uk](http://www.goldstandardsframework.org.uk)), that details prognostic indicators which help to identify the palliative stage in cancers and chronic illnesses, GPs are advised to use the 'surprise question' – '*Would I be surprised if my patient were to die in the next 12 months?*' – in order to identify patients who should receive active palliative and supportive care (Murray *et al*, 2005). Using this criterion, *all* patients with mesothelioma should be included in GPs' palliative registers at diagnosis and thus access palliative care routinely. A small evaluative study of the GSF suggests that it improves practice in primary care (Thomas and Noble, 2007) and GPs value its introduction (King *et al*, 2005).

The Preferred Place of Care document requires training of community nursing teams in advanced communications skills and palliative care before it is implemented and this has delayed its general implementation (Storey *et al*, 2003). Alongside these developments, charitable funding has provided for Macmillan GP Facilitator posts to improve knowledge of palliative care in rural Primary Health Care Teams (Noble *et al*, 2001). However only 14% of patients with mesothelioma died at home in contrast to the national average, around 26%, and against the 50-70% of cancer patients who wish to die at home (Table 3.28; Higginson *et al*, 1998; Gomes and Higginson, 2006); this supports the proposition of mesothelioma as a particularly burdensome disease.

Although the aim of improving end-of-life care by these three initiatives is laudable, they have attracted some criticisms. Finlay (2006) comments that 'the End-of-Life Care initiatives may help but cannot substitute for personal care'. The routinisation of care conflicts with the principle of individualised care espoused by hospice and palliative care and it has been suggested that these systematic approaches represent a further example of the medicalisation of a natural phase of life (Clark *et al*, 2002).

### *Hospice and voluntary sector care*

Patients with mesothelioma were found to access hospice services in over a third of cases, with one third of deaths occurring in hospices; in other cancers 18% die in hospices (Eve and Higginson, 2000). This is likely to be related to



two factors associated with hospice admission: precipitous functional decline and severe symptom burden (Teno *et al*, 2001; Clark *et al*, 2005).

The role of the voluntary sector in providing palliative care has now been acknowledged in the Cancer Plan (DH, 2000) to ensure 'realistic' funding for 'core services'. Macmillan Cancer Support is the only UK cancer charity that funds posts specifically related to mesothelioma: these include a combined lung cancer and mesothelioma clinical nurse specialist post, a part-time nurse consultant and an administrator running the charity, Mesothelioma UK, that provides information and advice to patients, relatives and healthcare professionals via a telephone helpline and the website: [www.mesothelioma.uk.org](http://www.mesothelioma.uk.org) and also runs educational events. The need for this service is evident from approximately 600 telephone calls per annum and over 20,000 hits on the website in 18 months (Mesothelioma UK, 2006).

## **7.5 Caring within the family**

The very term 'carer' causes problems for lay people: in Smith's study of 16 family caregivers less than half 'readily identified themselves as a carer to their loved one' and participants also described considerable confusion around the definition and role (Smith, 2001). Nevertheless, in this study the term is used to denote untrained lay informal family members who provided the majority of the care for people suffering from mesothelioma, the majority were wives of patients. Although acknowledging concerns around bereaved relatives' proxy accounts of patients' suffering (Addington-Hall and McPherson, 2001), these issues were only part of the experience of caring; this study was investigating the experience of mesothelioma and the bereaved relatives were primarily reporting their recollections of their individual experiences as carers.

### *The carer's role and responsibilities*

The roles and responsibilities of family members who take on a major caring role in the home have been well described (Brennan, 2004:134-9; Rose, 2001; Soothill *et al*, 2001). The extensive and often unfamiliar tasks of family caring at the end of life can be summarised as: personal care; emotional care; domestic care; management of finances and ongoing care of other dependents such as

elderly parents or children. Alongside the distress of trying to cope with the impending death of a lifetime spouse or partner and sharing the experience of their suffering, these carers' tasks are acknowledged to be exhausting, physically and emotionally, to the extent that, in cancer, carers' needs may exceed those of the patients (Harding and Higginson, 2003).

Family care giving is culturally situated: societal norms colour attitudes and expectations around caring at the end-of-life (Oliviere and Monroe, 2004:31). Rose (2001) postulates that, if caring is seen as a normal activity based on reciprocity and altruism, this might explain why caregivers expect little other than information from healthcare staff. Conversely, this could explain why the healthcare system does not have a systematic approach to supporting carers (Harris, 1998). In this study the bereaved relatives did not question the value or appropriateness of fulfilling the carer's role, thus supporting (traditional) society's expectation that wives in particular would provide care and comfort to ill spouses. Between 58 and 75% of carers are women (Lee, 2001b; Office of Population Consensus and Surveys, 1990) and Lee (2001b) revealed that although many women, particularly if older, internalised the 'natural' ethic of care; others felt that caring was a social imposition based on sexist assumptions. There is less written concerning the husband's role as carer but the two husbands of patients who were interviewed exhibited similar commitment to the caring responsibilities as the care-giving wives.

The study findings supported earlier work showing that younger women, in the 'sandwich generation' particularly, suffer from the burden of caring (Payne *et al*, 1999). Younger women were found to be more likely to have other caring responsibilities with regard to children and also elderly parents; in addition, being younger, the death of their husbands tended to be particularly untimely. Multiple caring roles were immensely demanding: for example, the mother of young children found that supporting their regular activities as well as their emotional needs as their father was dying put her under almost intolerable strain. Similarly, the daughter who was trying to cope with her dying father at the same time as work full-time and keep an eye on her elderly mother with memory impairment found the demands almost unmanageable. Rose (2001) describes the 'immense impact' of caring on 'normal' life for these women.

Nolan (2001a) identified two principles around carer support: firstly, family members should be enabled to make a fully informed choice as to whether or not they took on the carer role and secondly, they should be fully prepared for the role and given continuing support throughout the episode of care. However, although the bereaved relatives seemed glad in hindsight that they had been the main carers, spouses, usually wives, recalled that they had been precipitated into the situation of full-time caring without being given any option or consideration, as shown in previous studies (Rose, 2001; Nolan, 2001a). Family carers' expressions of pride that they had been able to care for their loved one and memories of appreciation of their efforts by the patients echoed previous reports: Rose (2001) describes the 'bittersweet' experience of caring in terminal illness in which the sadness of facing the death of a spouse is balanced to some extent by finding or making positive aspects of the situation and Nolan (2001b) describes the positive aspects of caring in terms of reciprocal care. Nevertheless, as illustrated in the focus groups, many relatives exhibited continuing distress and ongoing exhaustion, months or years into bereavement, related to their experiences as the main family carers.

From the focus groups with bereaved relatives it appeared that the patients' perspective of coping was not always shared by the carer due to the severe burden that caring imposed upon them: in most cases patients were determined to cope within the family setting and resisted outside assistance, as articulated in the coping narrative (p274-8). Carers who tended to follow the patients' wishes in choosing to manage without help until a crisis intervened or carer breakdown was imminent, evidently had many unmet needs and yet, paradoxically, were difficult to help. This has implications for the increasing tendency towards community-based care and challenges for supportive services. A common finding was that the care responsibilities usually fell to a single family member, often irrespective of their other responsibilities, and this sometimes led to resentment within the family. Randall and Downie (2006:75-84, 90-2) voice ethical concerns regarding policy initiatives that promote increased care of people with terminal illness at home in that these privilege the autonomy of the patients above the wishes of the family carer and ignore the potential impact on the carer. They also state that it is unethical to offer services that disproportionately disadvantage other patients or which cannot be adequately delivered, (Randall and Downie, 2006:183-9) for example, care in

the home usually needs support from community nursing teams but access may be difficult out-of-hours (Finlay, 2006).

In spite of the statutory entitlement of carers to an assessment of their own needs this did not appear to have been conducted formally in any of the families involved in the study (Carers' (Recognition and Services) Act, 1995). The practical difficulties of the home environment added to the strain for some carers. For example, one wife carried oxygen cylinders up and down stairs repeatedly – it would appear that she did not ask for assistance such as asking for them to be delivered to her husband's bedside (Box 5.12). Lee (2001b) reports that caregivers assumed that their health would suffer as a result of being a carer; as in the example above, this may thus become a self-fulfilling prophecy linked to carers prioritising the patients' needs above their own. Smith (2001), in her longitudinal study of family carers, demonstrates how carers' needs tend to be difficult to elicit given the privileging of (terminally-ill) patients' needs and the interconnections between the patients' and the carers' stories of the illness experience. Similarly, I found that in the interviews with patients, both patients and wives often spoke of 'we' with regard to the experience of the illness, as reported in the section 'In it together' (p184).

Social exclusion of patients with terminal illness also affects the family carers. Firstly the demands of caring may leave no time for outside activities and secondly, as demonstrated in the interviews with patients and in the focus groups, the patients often come to depend almost totally on their spouse. Whereas this may be the preferred situation for many patients, it causes additional stress for the carers who need to achieve some balance and have some time to themselves in order to mentally process the situation and adjust to it. Alongside bodily and mental changes affecting the patient, the physical withdrawal from society may amount to the 'social death' of the patient before their physical death; this invariably impacts on the carer too (Lawton, 2000:38). The importance of these issues affecting family carers with respect to healthcare service planning is included in Chapter 8.

In many cases, as shown by the interviews with patients and the focus groups, the reassignment of traditionally gendered roles, unavoidable in bereavement, had already begun during the illness; typically, wives, or sometimes adult

children, had no option other than to take on roles previously held by the husbands. However in some cases the illness had progressed so rapidly that there was no time to do anything than cope with the day-to-day demands. Living longer than predicted also caused difficulties: these included the carers' inability to plan ahead; problems for carers who needed to pace themselves in order to keep going for long enough until the death; practical problems relating to time off work; and not knowing when it (the demands of caring) would end, leading in one case to financial strains caused by numerous 'last' holidays.

An unexpected finding was that two bereaved wives disclosed that they had been asked by their husbands, both near death, to help them commit suicide. In both cases the wives understood these requests as reflecting unbearable suffering. In this small sample it is impossible to assess how common this is in mesothelioma but it does indicate, at very least, despair in these two patients, and distressing memories for their wives; it also raises questions concerning the support for these patients and their families.

### *Carers' needs*

The findings highlight the unmet needs of care-giving relatives in terms of information about mesothelioma and support, in common with studies in lung cancer (Krishnasamy and Wilkie, 1999:90). Relatives lived with constant anxiety as they tried to calculate the significance of symptoms, the stage of the illness and what time was left (Payne and Ellis-Hill, 2001:9; Rose, 2001:92); direct requests for prognosis appear to have been unsuccessful or in some cases overoptimistic, as reported in previous studies (Christakis and Lamont, 2000). The relatives, in both patients' interviews and focus groups, also revealed a sense of helplessness with regard to management of symptoms. Although it was clear that they felt personally responsible within the family for monitoring symptoms and often advising on and administering medication, none of them felt adequately informed about managing worrying symptoms and, in particular, when to call for help. Rose (2001) illuminates the emotional component from carers involved in giving pain-relieving medication when pain may be interpreted as evidence of impending death; additional factors may operate when the medication is morphine, given its association with death and addiction.

Relatives had wanted more information than the patients in order to predict developments and make plans accordingly, but in most cases they felt the information they received was inadequate. The Mesothelioma Information Service helpline (Box 6.6) appeared to be a useful national resource for people that accessed it and the charismatic, nationally known nurse running the helpline reported that she was contacted from far and wide. However, although most patients and relatives in this study had been given the information leaflet, none appeared to have contacted the helpline. These issues raise the question of how to provide information 'in the right amount, at the right time and in the right format' as recommended in the NICE guidance (2004). The challenge is to ensure that an individualised approach is adopted and that opportunities for provision of information are readily available for relatives (and patients) if and when they require them. However, as evidenced in the interviews with healthcare professionals, the clinical nurse specialists tend to be the ones whom patients and relatives approach for information, but some of these nurses were concerned that they do not have sufficient knowledge to answer all the questions concerning the relatively rare mesothelioma. This is not surprising given that the queries include medico-legal and State benefits issues, both complex and often changing, and theoretically outside the nurses' role. Recognition of carers' needs for better access to information has led to the development of information services funded by both the NHS and charities (Macmillan Cancer Support, 2006) although these are not yet widely available.

### *The burden of State benefits, civil compensation claims and the Coroner's investigation*

It is ironic and sad that, according to findings from patients, bereaved relatives and some specialist nurses, procedures for State benefits and, more particularly, civil compensation, cause additional suffering for many. Patients frequently appeared reluctant to claim State benefits, possibly a feature of the independence of this socio-demographic group. With regard to State benefits it is clear that without the assistance of specialist nurses or, occasionally, a benefits advisor, most patients would not have been able to navigate the complexities of the benefits system. A recent report has shown that less than 50% of cancer patients fail to obtain the benefits that they are entitled to (Macmillan Cancer Relief, 2004). In mesothelioma, the situation is even more

complex due to the specific criteria for Industrial Injury Disablement Benefit and the need for medical confirmation of the diagnosis; for some claimants, particularly those who are failing rapidly or very elderly, the system is unmanageable without skilled help. Specialist nurses were aware that this was not part of their official role but they felt obliged to take it on in the absence of anyone else.

In mesothelioma, apart from the above exhausting and demanding tasks for carers, there is usually significant work required to process claims for civil compensation. The patients felt under pressure to settle the claim before they died in order to be certain that their family would have financial security. This required frequent meetings with solicitors and sometimes appearances in court, an unfamiliar situation and worrying for anyone and particularly burdensome for ill people. This additional advocacy role was a major burden, particularly as future family financial security could depend upon successful claims. Patients often needed to trace former workmates to provide evidence in support of the claim; this was time-consuming and embarrassing. Some couples dealt with these together but usually the family carer, normally the wife, absorbed the extra workload. The civil compensation claims serve to remind the family of the occupational origin of mesothelioma and also emphasise the terminal nature of the disease: there is no escape from other reminders in the form of rapidly deteriorating health in most instances and specific State benefits such as Industrial Injuries Disablement Benefit. However there was also a sense that obtaining some form of financial compensation satisfied a need for retribution; although many patients and relatives discounted the monetary value of the award, they appeared to feel that it was evidence of a formal acknowledgement of culpability. In some way this was helpful and reflects the feelings of relatives bereaved by disasters, as described earlier (Riches and Dawson, 1998; Biddle, 2003).

The Coroner's investigation was mentioned by just two of the patients, fleetingly, at interview but was recalled as a major issue for the bereaved relatives. Two important points can be drawn from the findings: firstly the importance of ensuring that relatives are made aware of the statutory legal procedures, including post mortem examination and subsequent inquest, *before* the patient dies; and secondly, that the current system causes considerable

additional distress to bereaved relatives. This is explored more in the next section. Further, it was apparent that not all healthcare staff understood the status of mesothelioma as a prescribed disease and the medico-legal implications, and this led to serious distress and inconvenience for some relatives. Similarly, not all police officers working in these three high-incidence areas evidently understood mesothelioma, perhaps not surprisingly because junior officers may attend the death and the current legal procedures do not differ from those investigating a *sudden and unexpected* death that may be a criminal matter. Supportive and sympathetic Coroners (or their staff) were seen to make a considerable positive impact on the relatives' perception of the medico-legal process.

## **7.6 Bereavement after mesothelioma**

### *Experiencing bereavement*

There are no previous reports of bereavement following mesothelioma and in this section I will try to illuminate the experience of the bereaved relatives. The focus groups with bereaved relatives provided the data for this section but the findings must be seen in context: the focus group participants were self-selected volunteers and as such are likely to be a special group, that is, those relatives who probably had strong feelings about their experience of caring for someone with mesothelioma and who were able to attend and participate in a group. The groups were likely to have excluded people who were emotionally upset, or too unwell, or had other commitments or those who simply felt that they had nothing to contribute or who felt that the group may cause distress. Relatives who felt they had 'moved on' might also have been reluctant to participate.

There is a considerable body of literature on bereavement due to cancer and established models of bereavement relate mainly to bereaved married women from traditionally configured families (Valentine, 2006). The families affected by mesothelioma in this study tended to be similar and the widowed wives had mainly depended upon their husband's income, managed the home and family, and generally led conventional lives typical of their generation and socio-demographic group. The exceptions applied to the younger bereaved spouses:



they were more likely to be in double income families and in one case, the family included young children.

Since work by Freud in the early 20<sup>th</sup> century, many models of bereavement have been produced, notably the stages model of Kubler-Ross (1970), then the attachment theory of Bowlby (1980), later developed by Murray Parkes (1972) who illuminated the dynamic process of grieving. Recent theories stress the individual response to bereavement as depending upon personal resources and social contexts; in addition the contemporary notion of continuing bonds between the bereaved person and the deceased contrasts with earlier models that aimed at eventual separation from the dead person (Valentine, 2006).

The death of a spouse is acknowledged to be one of the most significant events in the life of an adult and has major psychological, social and physical impact (Thompson *et al*, 1991). Just as terminal illness disrupts and destabilises patients' and carers' biographies, bereavement has a similar impact on family carers. The crisis of bereavement can exceed a person's normal coping mechanisms. It requires an exceptional response and often new coping strategies. A new identity and 'mental map' is required (Attig, 1996:116-7) but finding the space and time required is particularly difficult in mesothelioma. Following mesothelioma, the newly bereaved person is often exhausted from the demands of caring, and usually involved in a worrying Coroner's investigation and possibly also facing further court appearances concerning civil compensation.

Anticipatory grieving, in which the loss of the dying person is thought about in advance of death and attempts are made to begin the adjustment process before the death, is considered to be helpful and to reduce the impact of the death (Costello, 1999; Sweeting and Gilhooley, 1990). This has been described as part of the 'dual process model' of looking forward and looking back, or 'loss orientation' and 'restoration orientation' (Stroebe, 1999). It might be thought that in mesothelioma the unavoidable reality of the impending death, reinforced by the lack of effective treatments, might promote anticipatory grieving, but the focus group findings did not suggest that this was usually the case. Most of the bereaved relatives described themselves as totally immersed in caring responsibilities: the demands of the physical and emotional care needs took up

all their time and energy and, due to the rapid progression of the disease and the severe symptoms, the majority did not have any time in which to think ahead and plan for a life without their partner. One wife, who had tried to think ahead whilst her husband was ill, had found it overwhelmingly distressing to imagine life without him (Box 5.14). Whilst trying to protect herself from this distress that interfered with her caring responsibilities, she described oscillating back and forth between the present and the future, between hope and despair, and trying to minimise thoughts of life alone in order to concentrate on the present, although painful thoughts still intruded – an example of the dual process of adjustment to forthcoming loss.

The carers' burden that involved social isolation, exhaustion, and change in role and identity during the illness (Lawton, 2000:105-8) was exacerbated by bereavement because now further major adjustments had to be made alongside the loss of their long-term partner. For almost all of the bereaved relatives in the focus group, at least three months into bereavement, the adjustment process was still active and emotions were still raw and uncontrolled. The one exception was the woman whose elderly mother had died peacefully at home: as described earlier this had been an example of a 'good death' in that it was timely, in the right place, peaceful and she had been ready to die. These factors obviously made her bereavement easier to adjust to and left positive memories concerning her mother's last few days (p191).

This 'good death' contrasted with the experiences of other focus group participants. Many gave accounts of extremely distressing deaths: uncontrolled symptoms; distressed patients; poor communication; lack of support; lack of preparation; and inability to keep the patient at home, all of which were all factors that contributed to difficulties in adjusting to the death. In many of these cases the mode of dying was recalled as being more distressing than the actual death, many relatives had felt unsupported during the terminal phase and exhibited distress around feeling that they had failed to achieve the best care for their loved ones. These feelings of dissatisfaction around the quality of end-of-life care were continued into bereavement and impacted on adaptation to bereavement as described by Rogers *et al* (2000).

Social isolation in bereavement after mesothelioma may be particularly severe because these relatives appear to become a marginalised group during the patients' illness. For some, relative poverty may have been another factor related to social exclusion as a result of low-paid employment throughout their adult life (Johnston and McIvor, 2000b). The lack of public knowledge of mesothelioma; the stigma associated with contamination and also with lung cancer; the involvement in litigation and, particularly relevant to Barrow, continuing to live in a town where the industry responsible for the mesothelioma is still the major employer; all contributed to a sense of alienation. Public sympathy for loss due to cancer is compromised by these factors, alongside the difficulty for bereaved relatives in relating the dire circumstances of the illness and the shattering experience of the caring. Society likes happy or at least acceptable endings; this is not usually possible with respect to mesothelioma in which the bereavement process is impaired by ongoing medico-legal processes. In these circumstances the retrospective 'heroic narratives' become particularly important.

### *Mesothelioma as 'disaster'*

The focus group findings suggest that bereavement following mesothelioma echoes reports of bereavement after disaster (Riches and Dawson, 1998; Mead, 1996). The common feeling in the bereaved relatives that deaths due to mesothelioma should be regarded as 'mass murder' takes it into the wider political arena of culpability, corporate manslaughter and the need for society to acknowledge and recompense the injured parties. There are significant differences however between deaths due to mesothelioma and the public perspectives of deaths due to disaster. Most disasters involve multiple deaths all occurring at the same time and usually in the same place; neither is true for mesothelioma deaths. The usual disaster response is extensive media coverage that frequently results in public sympathy, extending to practical support in terms of financial aid and also imparts knowledge to the public. This does not occur in relation to mesothelioma. Bereavement by disaster intensifies grief and, typically, those bereaved by disaster exhibit anger and resentment and expect retribution and reparation from the perpetrators (Lee, 1994; Riches and Dawson, 1998; Mead, 1996).

In mesothelioma the employers in the industries where asbestos exposure had occurred provided an obvious focus for the anger of the bereaved relatives. Other factors that may increase the outraged reaction of relatives may be the lack of public awareness of deaths in spite of the 'mesothelioma epidemic' (Peto *et al*, 1999) and the lack of the usual social response, although the medico-legal processes are identical in typical disasters and mesothelioma. Other social factors may prevent publicity around mesothelioma and these mirror the elements of disadvantage experienced by the patients and their relatives: the age of the patients; the cancer diagnosis; the interval between cause and effect; the lack of effective treatments, and the small numbers in most localities.

In their heated discussions and emotional outpourings it was clear that the bereaved relatives in this study felt that neither the societal nor the medical response to mesothelioma came up to their expectations. Following the traumatic experience of the patients' illness, through the off-putting complexities of the State benefits system, the worry and threat involved in litigation for civil compensation, from the indignities and offence they experienced due to the post mortem and inquest, these bereaved relatives felt as if they were engaged in one struggle after another and that there was no prospect of closure even after the death. Lack of medical knowledge about mesothelioma; lack of attention to symptom control, and lack of appreciation of the role and needs of family carers were seen as major failings of the healthcare system. Perhaps linked to their social isolation, they also felt as if nobody really knew or cared about their plight. Experience from disasters such as the Hillsborough Stadium disaster<sup>96</sup> and the sinking of the Herald of Free Enterprise<sup>97</sup> suggests that compensation claims for psychological impact, particularly for post-traumatic stress disorder (PTSD), may represent a symbolic recognition of loss that is not fulfilled by the usual legal process. Some of the relatives' accounts revealed features of PTSD, such as flashbacks and intrusive thoughts, confirming the horror of the experience (Mead, 1996).

These features, alongside the stigma associated with mesothelioma, all contributed to 'spoiled memories' of the dead person (Riches and Dawson,

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<sup>96</sup> The Hillsborough Stadium disaster occurred at a football ground in Sheffield, Yorkshire in 1989. Restraining barriers gave way and 96 people died in the crush.

<sup>97</sup> The Herald of Free Enterprise was a North Sea ferry that sank off Zeebrugge in 1987 because routine checks to ensure vital doors were shut had not been conducted causing 197 deaths.

1998). Deaths due to mesothelioma can be considered to be 'meaningless' deaths and have features in common with other unexpected, avoidable, sudden or untimely deaths such as the murder of a child or deaths due to disasters as mentioned above. The difficulty in finding meaning in death due to mesothelioma interferes with the construction of a helpful or restitution narrative around the experience and further hinders adaptation to the loss (Riches and Dawson, 1998). Social isolation adds to this by reducing opportunities to tell and retell the story, as confirmed by the cathartic value of the focus groups for some participants. Spoiled memories also impair the 'continuing bonds' that current bereavement theory proposes are helpful in grieving (Klass *et al*, 1996). Attig (1996), mentioned above, describes bereavement as a process of 'relearning the world' but the medico-legal processes that are designed to establish the official cause of death both disrupt and delay the normal adjustment and 'hold people in the past' by concentrating on negative issues such as blame, accountability and the burden of the disease. In these circumstances it is not surprising that, as in this study, bereaved relatives develop narratives of dying that emphasise the 'victorious' or 'heroic' death: these narratives assist in forming a coherent meaning around the experience that assuages emotional distress, counters the negativity and restores the moral reputation of the traumatised carer, another example of a restitution narrative (p274).

However not all the consequences of bereavement were negative and in some cases the experience of caring had created significant personal development in terms of self confidence and pride in having coped well with a devastating situation. Valentine (2006), in her review of bereavement studies, points to the development of self-help organisations by stigmatised and marginalised groups of bereaved people, illustrating both the lack of statutory services and a growth of individual action. Two of the bereaved relatives belonged to 'asbestos victim support groups'<sup>98</sup>. This could also be regarded as a positive bereavement outcome in which emotional energies were redirected to a constructive activity that also rebuilt self esteem and identity, fulfilled the need for action, was socially acceptable, and satisfied altruism; it may also have been a way of continuing a connection with the dead relative in a way that contained emotional distress.

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<sup>98</sup> At least 2 more bereaved relatives joined support groups following the focus groups.

The severity and complex nature of the bereavement after mesothelioma has not been described previously and the issues that have been raised by this study merit acknowledgement of the devastating experience, both during and after the episode of illness, for family care-givers and special attention from supportive services. The role of some support groups in welcoming bereaved relatives is to be applauded but this is not appropriate for all and, given the social isolation and reluctance to seek help for themselves exhibited by many carers, perhaps a proactive approach to supporting this group of people is needed?

## **7.7 Users' views of services**

Small and Rhodes (2000:56-85) examined the difficulties in accessing the views of patients who may be literally 'too ill to talk' and highlighted the complex issues surrounding user involvement, particularly in terminal illness. In addition, patients facing death are unlikely to criticise their healthcare services when needing to rely on them in a 'life or death struggle' (Frank, 1991:112). Another factor is the tendency for women to be more critical of healthcare services than men; thus terminally ill men with mesothelioma are very unlikely to voice complaints (Anderson *et al*, 2001). The bereaved relatives' dissatisfaction concerned the following areas: communication and information, inefficiencies and poor practice. This is important because dissatisfaction with healthcare is related to poor bereavement outcomes (Coyle, 1999; Rogers *et al*, 2000). It must not be forgotten that the patients and the bereaved relatives were very different samples and, in particular, the relatives were looking 'through the lens of loss' and, as mentioned earlier, were particularly likely to have a story to tell.

### *Communication and information*

In contrast to the patients, bereaved relatives voiced many criticisms of the care received and three were wondering if they should make an official complaint, sometimes many months into bereavement. Some of the issues have been raised above but there were serious issues around poor or inadequate communication, particularly at the time of disclosure of diagnosis. The breaking of bad news is now specifically taught in medical undergraduate and postgraduate education and NICE guidance (2004) stipulates that doctors who

are in a position to be dealing with bad news consultations should receive appropriate communication skills training. Perhaps mesothelioma is a particularly difficult diagnosis to disclose given the lack of effective treatments, the poor prognosis, the relative rarity of the condition and the attribution to asbestos many years earlier. Some relatives clearly perceived 'medical nihilism' as described in the BTS (2001) statement on mesothelioma.

As noted earlier, relatives' information needs differed from, and were often greater, than those of the patients. The status of relatives with respect to the patients in the healthcare system was unclear, both to the relatives and apparently to some healthcare professionals: in some cases they felt excluded by incorrect interpretations around confidentiality but this contrasted with the occasions on which spouses were told the diagnosis before the patients. Relatives may be regarded as 'secondary patients' but this creates tension with the traditional doctor-patient relationship (Randall and Downie, 2006:75-7). In mesothelioma, where time is short and the disease so devastating, and where the burden of most of the care usually falls on the nearest relative, there needs to be clarity around the position of relatives for individual patients, including how much information the patient wishes them to receive.

Problems around information with regard to complex treatment decisions caused some distress but this is not straightforward (Box 5.5). In serious illness many patients, particularly if elderly, would rather follow advice from senior doctors that they trust than be given complicated choices that they may not fully understand (Small and Rhodes, 2001:73). In mesothelioma, where there is no standard management plan, and where relatives may obtain confusing and conflicting information from different sources including websites, it is clear that, as in many terminal illnesses, a trusting relationship with a doctor who communicates well is greatly supportive to patients and their families. However it appears that patients and families with mesothelioma are in a situation that appears to give mixed messages: they were told that there were no active curative treatments but then experienced repeated emergency admissions for life-saving treatment of pleural effusions. These episodes created severe anxiety because, on every occasion, both patients and relatives feared that death was imminent (and in some cases this was true). This leads to the reflection that patients and their relatives did not appear to understand the likely

course of the disease and to question whether having more information, for example, about the likelihood of recurrent pleural effusions and how to recognise early signs, might reduce the number of crisis admissions. This is compounded by lack of up-to-date management of pleural effusions, particularly since the introduction of the indwelling pleural catheter<sup>99</sup>.

With regard to chemotherapy it was evident that opinions were divided: hospital doctors tended to see the utility of recruiting patients to trials in the hope that eventually effective treatments would result, whereas community doctors and nurses, who may have had closer relationships with patients and their families, tended to see the matter in terms of the impact and opportunity costs for the individual patient and their family. This has to be seen against the lack of any effective chemotherapy to date and the delicate balance between the ethics of patient autonomy when patients are willing to try anything that may help (Slevin *et al*, 1990), resource implications, distributive justice, and beneficence. Interestingly, a recent audit of treatment received by patients with mesothelioma in Leeds revealed that of the 36% considered fit for chemotherapy, just over half refused the option, thus 17% proceeded with treatment (Chapman *et al*, 2006).

Frank (1991:56) describes the sensitivity that patients with cancer exhibit with regard to communication with doctors and this is dependent on the individuality of both participants (Freeling and Gask, 1998). The doctor's comment that caused great offence to one wife when she expressed concern about her husband's poor appetite - 'feeding the tumour' (p182) - was meant to be reassuring but had the opposite effect. Interactions that were perceived as unfeeling, dismissive or demeaning, caused great distress and destroyed relationships between patients or their families and healthcare professionals.

### *Inefficiencies*

Access to treatments was affected by distance, the 70 miles from Barrow to radiotherapy and the 80 miles to the nearest thoracic surgery centre discouraged some patients and may have impacted on referrals from doctors, although that is not proven in this study. Similarly the distance to centres where radical surgery was performed also appeared to discourage referrals from Barrow but other factors were not examined, the situation was easier for all

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<sup>99</sup> Described on page 26



referrals in the other 2 sites. This concurs with Cosford *et al's* study (1997) that found that travel times of more than an hour reduced uptake of radiotherapy. Counter-intuitively, a literature review examining the impact of travel times on cancer patients described the evidence for a negative effect of long travel times on psychological distress, compliance, and uptake of services, as inconclusive. However the study concluded that travelling far can be inconvenient, a practical hardship and 'may be perceived or experienced as a barrier to treatment by patients' (Payne *et al*, 2000; Jarrett *et al*, 2000)

A low referral rate (49%) to palliative care was evident from the medical records survey, although this reflected practice a few years earlier than that received by the patients interviewed and referred to in the bereaved relatives' focus groups; indeed, most of the bereaved relatives reported accessing hospice services. All three study sites had hospices in their localities and all these hospices worked closely with NHS palliative care services. Increasing awareness of palliative care services and mesothelioma may have contributed to this difference. However it is not surprising that hospice care featured in a third of the 80 medical records cases given the high symptom burden and demands on carers. Carer exhaustion is a common reason for hospice admission at end-of-life (Hinton, 1994) and was reported by most of the bereaved relatives.

Many problems related to inefficient follow up arrangements including obtaining results of investigations and resourceful relatives had attempted to 'beat the system'. Out-of-hours GP services also caused problems, in particular, concerning access to opioid medications when duty doctors were unfamiliar with the patients (Worth *et al*, 2006; Small Practices Association, 2006). This lack of efficiency added to the distress of patients and relatives.

In addition to relatives' perceptions that doctors, particularly junior doctors, often did not know much about mesothelioma, relatives also reported apparently unsupervised and inexperienced junior doctors performing invasive procedures in three cases. This clearly disturbed the relatives but also demonstrates the power imbalance between patient/relative and doctors as no complaints were made at the time of any of the three incidents.

## 7.8 Reflections on the research process and methods

Looking back I feel that the study answered the research questions reasonably well, given the constraints and limitations described in the methods chapter (pages 89-100). However, some improvements or amendments need to be considered. In the original proposal I had planned to conduct more than one interview with each patient; in the event, practical considerations resulted in single interviews in every case. This is regrettable because there was little opportunity for the patients to develop a trusting relationship with me (only one patient knew me before the study). If a longitudinal study had been conducted data concerning spiritual matters or psychosocial distress may have been more evident. These data were noticeably lacking from most of the interviews and yet previous work around psychosocial distress in relation to cancer site and severity of physical symptoms (Zaborra *et al*, 2001) would suggest that, in mesothelioma, these would be likely to be major issues. Given that a 'coping narrative' helps patients to reduce emotional distress in mesothelioma it is unlikely that patients would disclose potentially upsetting issues unless they felt secure and trusted the researcher. However, as an experienced GP and hospice doctor, I am practised in establishing professional relationships in a short time. Patients may have chosen to concentrate on physical issues due to their own preconceived ideas about what would be most relevant to disclose to a researcher who was a doctor. It would be interesting to examine any difference in issues raised if, in future studies, the researcher was non-medical, for example, a psychologist or social worker. A longitudinal series of interviews would also have explored the changing experience of mesothelioma for individual patients and their families over time.

A noticeable feature of the interviews with patients was that all but one of the patients' spouses were present although this was not specified on the invitation; this linked to the theme of 'in it together' (pages 153-5). The interviews were not intended to be with couples but it may have been helpful to conduct some joint interviews with patient/family-caregiver dyads: this may have more accurately reflected the lived experience of mesothelioma, given the evidently close relationships in these couples and the apparently jointly agreed coping strategies revealed in some of the interviews.

A longitudinal study incorporating serial interviews with patient/family-caregiver dyads during the illness and subsequent interviews with the spouse in bereavement would have additional value. Ethical issues would need careful consideration, in particular the need to ensure that consent was reconfirmed at all stages and that support for grieving relatives was available.

Similarly, serial interviews with healthcare professionals may also have provided richer data than single interviews. It is possible that some of the participants may have been reluctant to appear critical of their local services, particularly to an unknown researcher who was also not local. Similarly, participants may have been reluctant to speak freely about their own or the profession's knowledge gaps to a stranger.

A deficiency in the design of the study was the lack of involvement of community (district) nurses who provide the majority of 'hands on' care for terminally ill people in their own homes. This reflected a practical problem: District nurses work in teams and, in a small study, it may have been difficult to easily identify nurses who had significant experience of nursing patients with mesothelioma at home. Adding another data source would also have made the study unmanageable for me as a single researcher but should be considered for a future study. Similarly, given the findings that revealed the severity of the bereavement reaction following mesothelioma, investigation of the experience from the perspective of people providing bereavement support services would complete the picture and is again a topic for future study.

However, all the above suggestions would have greatly increased the workload and could not have been incorporated by me as a single researcher without reducing other parts, and this may have impacted on the findings. Conducting this multi-method study as a single researcher gave me a unique perspective on the weight of the various findings and enabled me to draw them together to produce a comprehensive integrated account.

### *In summary*

In this chapter I have discussed the main findings from the study. In the final chapter I will restate what I set out to do and evaluate the study against these original intentions. I will outline the findings and, in particular, new findings, with regard to the implications for service provision and further research. I will also review the study in terms of the palliative care perspective and the tradition of social medicine.

## Chapter 8: Conclusions

The intention of this study was to produce a comprehensive account of the experience of pleural mesothelioma in Northern England from the perspective of palliative medicine and in the tradition of social medicine. The study was designed to answer the following research questions:

- What is the experience of pleural mesothelioma for patients and their families?
- What is the experience of pleural mesothelioma for healthcare professionals and service providers.

In this final chapter I review the extent to which each of the research questions has been answered, draw out the main messages from the study, and indicate how the study contributes to existing knowledge. This is followed by my reflections on the study following the tradition of social medicine and from the perspective of palliative care. I conclude with consideration of some of the implications of the study for service provision and research in palliative and supportive care relating to mesothelioma.

### *What is the experience of pleural mesothelioma for patients and their families?*

This study expands upon the few previous sociological and medical accounts of patients' experiences of mesothelioma, confirming that these patients face a particularly difficult set of circumstances. The major features of experiencing mesothelioma as a patient are as follows: the disease usually presents acutely with frightening symptoms of breathlessness and/or pain; the diagnosis is often delayed; multiple invasive interventions are required for diagnostic and therapeutic purposes; the illness is hard to bear with a severe symptom burden and rapid physical decline; multiple hospital admissions, often as emergencies and involving several hospitals, are required in the last year of life due to recurrent pleural effusions or medical interventions; a small number receive chemotherapy and few patients are deemed suitable for surgery and virtually all patients are made aware that these treatments are not curative. Due to the distressing nature of the symptoms and erratic trajectory, relatively few patients die at home and 'bad deaths' are not uncommon. Moreover, although some patients may be aware that they are at risk of mesothelioma, the disease is not widely-known by the public, and medical knowledge may also be inadequate. In

spite of the severe symptom burden, the study revealed that less than half the patients were referred to palliative care and in many cases this was at a very late stage.

The study provides the first detailed account of the experience of mesothelioma from bereaved relatives who had been the main informal carers. Although the bereaved relatives' focus groups inevitably provided retrospective accounts through the lens of loss, and were more emotional than accounts from patients' interviews, they largely agreed with the patients in emphasising the delays in diagnosis, severe symptoms, unpredictability of the illness, rapid deterioration in health, and the anxiety of not knowing what to expect or what to do to help. The role of main family carer was illuminated as requiring a considerable commitment, not only with regard to the well-documented physical and emotional labour tasks, but the family carers of patients with mesothelioma frequently took on the main responsibility for dealing with medico-legal matters, as in the following section. This was endorsed by the data from healthcare professionals, particularly those working in community settings.

*What are the psycho-social aspects of the experience of mesothelioma for patients and their families?*

The psycho-social issues around facing death due to terminal illness have been well described but this study demonstrated that mesothelioma differs in several areas that affect both patients and their families: causation due to occupational exposure to asbestos brings a number of issues concerning attribution and blame, specific State benefits, and civil compensation; patients are made aware that there is no cure: for many patients this is interpreted as 'there's nothing they can do'; the disease is unevenly distributed, relatively rare, and public knowledge is poor, therefore public support for patients and their families is less assured; and, in addition, patients and their families may have background awareness of asbestos-related disease that give rise to anticipatory anxiety. In mesothelioma, anticipatory anxiety concerns not only the worries around the possibility of developing the disease but, following diagnosis, focuses on feared symptoms such as severe pain or breathing difficulties and a 'bad death' based on knowledge of other sufferers. The study also revealed that, once the diagnosis had been confirmed, many patients and their relatives felt that they were 'in limbo' without any plan of treatment and this created a sense of

abandonment and neglect, in contrast to their hopes and expectations. Confusion and disappointment regarding oncological treatments and radical surgery added to the sense of disadvantage. This mirrored the frustrations expressed by healthcare professionals at the lack of standardised management of mesothelioma and their distress at the lack of effective treatments. As in previous accounts of cancer patients' views on the services they received, trusting relationships with key healthcare professionals were essential in supporting patients and their families.

The 'narrative of coping' adopted by patients in order to manage the emotional distress and devastation of mesothelioma has not been described before. Exploration of this concept illuminated various reasons why this narrative may be utilised by patients to help them deal with their illness but, paradoxically, that it hinders access to palliative and supportive services.

The case study method, incorporating mixed methods and multiple data sources, revealed some differing perspectives and this was particularly noticeable with respect to the emotional tone of the patients who were interviewed compared with the bereaved relatives' accounts. Stoicism and controlled emotions on the part of the patients contrasted with the highly emotional and often angry accounts from bereaved relatives in the focus groups. These varying accounts reveal the multi-layered nature of human experience and, although not intended to compare 'like with like', nevertheless illuminate some of the complexities in mesothelioma that are faced by patients and relatives.

The study illuminates the ways in which the situation may often be exacerbated by the very systems that are designed to provide financial assistance, namely the complex and burdensome State benefits and civil compensation procedures. The apparently common practice of combining disclosure of the diagnosis with advice on claiming State benefits and seeking civil compensation was distressing to some patients and, to a greater extent, to relatives. Failure to pre-warn relatives about the necessity for a post mortem examination and inquest created additional distress. Reactions to the Coroner's investigation were mixed, and insensitive handling caused further trauma to newly-bereaved relatives.

The study provides the first account of the experience of mesothelioma for family carers. Although many unmet needs were identified by bereaved relatives, this was complicated by the tendency for families of patients with mesothelioma to be caught up in the 'narrative of coping' which inhibited them, as well as the patients, from accessing supportive services. As in other studies in cancer, relatives felt under-rated by healthcare professionals, particularly in secondary care, and dissatisfied with the style and content of information provided. This was frequently exacerbated by the burden of State benefit claims and civil compensation procedures, and then, after death, by the Coroner's investigation.

Particular issues concerning bereavement after mesothelioma have not been reported before. The study suggests that the severity of bereavement following mesothelioma appears to relate to the avoidable causation of the disease, the lack of effective treatments; the distressing symptom burden; the unpredictable disease trajectory and rapid decline; and, often, a bad death. In many cases relatives had not been prepared in advance for the post mortem and inquest and this study supports a previous small audit which advised that relatives should be informed about the Coroner's investigation before the patient dies. The study highlighted an almost complete lack of support for bereaved family carers in mesothelioma. The relatives' description of deaths due to mesothelioma as 'mass murder' goes some way to explain the similarities with reactions following death due to disasters and features of 'tragic grief'.

*What is the disease trajectory, disease burden, and service usage in mesothelioma?*

Although descriptions of the course of mesothelioma have been written previously, this study provides the first graphical representation of the disease trajectory, based upon quantitative and qualitative data. This image demonstrates that mesothelioma differs from the 'cancer trajectory' typified by a slow deterioration over years followed by a more rapid decline in the final few months. The depiction of the mesothelioma trajectory reinforces the particularly disruptive nature of the disease due to its erratic course and suggests that a more proactive approach is required in order to minimise the impact of the disease.



This study supports previous work suggesting that the disease burden in mesothelioma is particularly high in both physical and psychological terms. This has implications for service provision – although not wishing to endorse a ‘league table’ of suffering in cancer, and accepting that all terminal illness is devastating, nevertheless, the particular set of unique circumstances faced by patients with mesothelioma and their relatives as demonstrated by this study, would appear to demand that they should be receiving better services than they currently access.

The study demonstrates that from healthcare professionals’ perspectives, mesothelioma is associated with many challenges. The difficulty in achieving diagnosis not only worried patients and relatives but was also distressing for the professionals, and was common, even in the three high-incidence areas involved in this study. Lack of a standard approach to management also caused particular difficulties although a contrasting view emphasised the need for individualised care and would mirror the emphasis on holistic person-centred approach of palliative care. The acknowledged problems in achieving symptom control also distressed professionals although the findings may suggest that, with modern palliative medicine, the numbers of patients with truly refractory pain may be smaller than previous accounts indicate. This links to the discussion (page ref) regarding interventional analgesia, particularly cordotomy, and raises questions around the need for invasive procedures in all but a tiny minority if all patients accessed specialist palliative medicine.

Service usage was demonstrated by the medical records survey and showed that patients with mesothelioma spend the time from diagnosis to death encountering a variety of health services in multiple venues. Although the majority of the last year of life is spent at home, the burden of repeated emergency admissions could be minimised by more effective management of pleural effusions, and an open access arrangement to respiratory wards and/or patient-held records that included diagnosis and management guidance. The tensions around the centralising of specialist services against the wishes of the patients and relatives to have local services were evident in the study.

*From the palliative care perspective* the study suggests that the usual medical approach to the management of pleural mesothelioma tends to be structured in a way that reflects better outcomes in other cancers rather than reflecting the fatal reality of mesothelioma. The study highlighted the fact that, in common with other cancers, patients with mesothelioma, who virtually all need palliative care expertise, are not accessing it either early enough or at all, in spite of this being recommended practice. The management of mesothelioma in the community was shown to rely heavily on primary care teams and these occasional patients could entail a considerable workload, particularly for GPs, District nurses and Macmillan nurses. Lack of resources and inadequate knowledge plus lack of access to expert advice on State benefits were seen to disadvantage patients with mesothelioma. Ensuring that all patients with mesothelioma are entered onto primary care palliative care registers should link patients to end-of-life care initiatives including the Preferred Place of Care Document and increase the likelihood of patients and their families being helped with advanced care planning.

Dealing with patients with a rapidly fatal disease, distressing symptoms, and, sometimes, angry relatives, has a significant emotional impact on healthcare professionals and this does not appear to have been previously acknowledged with respect to mesothelioma. Whereas the nursing profession does put support in place in terms of clinical supervision, albeit not necessarily adequately, medicine has no system for this and traditionally ignores the emotional issues for doctors in caring in distressing situations.

Thus from a palliative care perspective, mesothelioma would seem to be a striking example of the 'inverse care law' in that this group of severely symptomatic and psychologically distressed patients fail to be referred early, if at all, to specialist palliative care. This needs to be addressed in a systematic way and not left to patients to request assistance; as shown by the discussion of the 'narrative of coping', patients with mesothelioma, and their relatives, are unlikely to ask for assistance, even when it is clearly required, until a crisis occurs.

*Viewed from the tradition of social medicine*, mesothelioma, as it affected the patients and families in this study, reflects the social context of the post-war

years and the risk-taking macho culture of that era. Sadly it also reflects major neglect of asbestos hazards in the workplace in spite of increasing regulation from 1931, and more recently, 1969. Mesothelioma should be a public health priority as UK deaths now exceed those from cervical and other well-known cancers. As the most common fatal industrial malignancy, and one in which 25% of deaths are now occurring in the building trades, the changing epidemiology demands a robust approach to asbestos hazards advice, in particular concerning asbestos in domestic and commercial buildings. The changing distribution, away from centres of traditional heavy industry, to a more generalised distribution, also poses a challenge to public health in terms of risk education and service provision. The social medicine perspective also illuminates the interaction of industrial, social and medico-legal issues that exacerbate the situation of people affected by mesothelioma and explains some of the anger due to a sense of betrayal by government agencies, employers and the insurance industry, alongside distress around the severe physical impact of the disease and lack of effective treatments (LaMontagne and Walker, 2005).

#### *Implications for service provision and research*

The challenges to healthcare service providers are clear: there is a need to develop appropriate and acceptable palliative and supportive care services that patients with mesothelioma access as a matter of routine practice early in their illness. Similarly, supportive services for relatives caring for someone with mesothelioma need to be an integrated part of routine care, and, importantly, must include bereavement care. I suggest that this could be operationalised by appointing a Lead Palliative Physician for mesothelioma alongside the Mesothelioma Lead Physician and Lead Nurse in each Cancer Network. The intention would be to provide '*palliative care in parallel*' with oncological treatments or to support primary health care and palliative care teams in patients with advanced disease. The Lead Palliative Physician could also deliver an educational programme about mesothelioma in collaboration with the Network Lead Physician and Nurse and also collaborate in research. These Network Leads could link to specialist centres for mesothelioma, ensuring that appropriate patients were able to access surgery or newer interventions but, hopefully preventing inappropriate referrals.

These issues set the agenda for future research and, as the European mesothelioma epidemic nears its peak, there should be no delay. The Australian and U.S. governments have provided state funding for research in mesothelioma and, with an incidence only second to Australia, state funding for mesothelioma research is long overdue in the UK. The situation is dire in the resource poor countries where unregulated active asbestos industries continue and sadly ensures a continuing legacy in terms of future patients with mesothelioma; in their circumstances palliative care is likely to be the only economically viable approach.

The implications for research posed by this study focus on the following questions:

1. How can we ensure that patients with mesothelioma receive the palliative and supportive care services that they need and when they need them?

One suggestion would be to incorporate routine referral to palliative care at point of diagnosis into the Mesothelioma Framework. This could be supported by the routine use of an assessment tool such as SPARC<sup>100</sup> on diagnosis of mesothelioma. This intervention would need to be evaluated, possibly by means of a study in high incidence areas, before wider dissemination.

2. What are effective interventions in the management of pain and breathlessness in mesothelioma?

This could be addressed by prospective investigation of standard specialist palliative interventions in mesothelioma including non-pharmacological interventions shown to be effective in other conditions. This could possibly lead towards the development of an evidence-based guidance or care pathway that would marry oncological interventions and best practice management of pleural effusions with palliative interventions, the concept of '*palliative care in parallel*'.

3. What are effective interventions in the psychosocial areas in mesothelioma for patients and their family carers?

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<sup>100</sup> SPARC is the Sheffield Profile for Assessment and Referral to Care, a questionnaire that asks about physical and psychological symptoms, social concerns and information needs with respect to the preceding month. It can be completed by the patient, a relative or administered by a healthcare professional.

The study reveals deficiencies with respect to information, communication and emotional and practical support, mirroring work in cancer in general. Fragmentation of care between multiple professionals and patchy professional knowledge of mesothelioma exacerbate these problems and leads to the suggestion that perhaps patients with mesothelioma would benefit from access to a key worker, for example, a clinical nurse specialist with accredited training in mesothelioma. A key worker could also facilitate communication between primary and secondary care professionals and ensure that patients were included in the end-of-life care programme. This type of service would need to be set up as a research project and evaluated.

4. How can services be organised most effectively for patients with mesothelioma?

This is the remit of the newly-released Mesothelioma Framework which suggests consideration of mesothelioma MDTs, specifically lung cancer MDTs that deal with a minimum number of cases of mesothelioma, in order to improve the quality and consistency of care. This study would support this concept and would also suggest the inclusion of a palliative physician in each mesothelioma MDT meeting.

5. How can relatives of patients with mesothelioma be supported during the illness and in bereavement?

The explanation of the 'coping narrative' indicates that supportive services need to be proactive in order to overcome the reluctance of relatives, as well as patients, to ask for assistance. Specific carer assessment tools, for example the Carer Strain Index, (Robinson, 1983) could be evaluated in mesothelioma with the intention of pre-empting crises and reducing carer strain.

A problem with the current model of support from clinical nurse specialists is that they do not provide ongoing support for relatives into bereavement. Bereavement research would suggest that ongoing support from a professional who knew the family during the illness and continued during bereavement might produce better outcomes; again, this would need to be set up as a project and evaluated.

In conclusion, the lack of effective care of patients with mesothelioma and their families is a sad reflection on multiple disadvantage as this dreadful disease mainly affects older men from the 'traditional working class'. Indeed, the whole story of the experience of mesothelioma can be summed up as one of disadvantage, devastation and difficult dying. Cassell (2004: v) states that '*the test of a system of medicine should be its adequacy in the face of suffering*'. This study reveals many inadequacies in the care of patients with mesothelioma who are experiencing severe suffering, and also in the support of their family carers. I hope that this study will go some way to informing the development of services and research in palliative and supportive care in order to improve the care provided to patients with mesothelioma and support for the family members who care for them.

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## **APPENDICES 1-13**

### **Appendix 1: INFORMATION LEAFLET for BARROW PATIENTS**

#### Research title:

Palliative Care in Mesothelioma: What are the needs of patients and their families?

#### Aims

To understand the meaning and experience of Mesothelioma from the perspective of patients and their families, to understand more about the disease and its impact on patients and their families and to use this information to develop recommendations for service developments and further research into Mesothelioma.

#### Background

Barrow in Furness has a high incidence of Mesothelioma due to asbestos usage in the shipyard many years ago although not all cases are related to shipyard work. The published literature on Mesothelioma mainly relates to research into possible treatments for this condition, very little is written from the patients' point of view. It is now national policy to incorporate the views of patients into the planning of health service developments and the first step is to understand how patients experience the illness and its management.

#### Method

7 patients with Mesothelioma from the Barrow area will be recruited to take part in the interview part of this study. They will all be given this leaflet and can ask their Macmillan nurse or the Lung Specialist nurse for further information if necessary. Patients who are willing to volunteer to be interviewed will be asked to sign a consent form which will be explained to them and countersigned by the Macmillan or Lung Specialist nurse. The rest of the study includes a review of hospital and GP records of patients with Mesothelioma and interviews with doctors and nurses working in this field and groups of relatives. In order to obtain a view of the situation for Mesothelioma patients in different areas and circumstances the study will be carried out in Leeds and Doncaster as well as in Barrow.

### Researcher

Dr Helen Clayson has been a GP in Kirkby-in-Furness since 1980 and is also Medical Director of St Mary's Hospice, Ulverston. At present she is on 12 months study leave from the practice to do this research and is registered as an MD student at Sheffield University. Her particular interest in Mesothelioma arose from looking after people with this condition and realising how little was written about the patients' experience of this disease.

### Interviews

Dr Clayson will visit people in their homes to conduct the interviews. She will wish to talk to you about the following areas: Family background and occupational history, the onset of the disease and medical interventions, the impact of the disease on you and your family and coping with the illness. The interview should take around 1 hour. You can refuse to answer any of the questions and will have the opportunity to raise any other important issues if you wish.

### Data handling

The interviews will be recorded onto mini-disk and then this data will be transferred onto a word processor for analysis by Dr Clayson. The disks, tapes and any written data will be kept securely locked when not in use by Dr Clayson. All information from the interviews will be covered by the Data Protection Act. The tape recordings will be destroyed at the end of the study by the researcher.

### Results

The results of the interviews will be written up and submitted as part of the MD thesis and may be also submitted for publication as whole or part of articles in peer-reviewed professional journals. No details of individual patients such as name, address, date of birth or other identifying features will be included in the reports; patients will be identified by allocated numbers. In the event of the researcher wanting to publish any potentially identifiable information, e.g. a direct quotation from an interview, specific consent would be sought from the patient concerned and the information not published unless consent had been

given. At the conclusion of the study a summary of the research findings will be available for patients and families who have taken part if they wish to see it.

Invitation to participate

If you wish to take part in this study your Macmillan nurse will ask you to sign a consent form. You are fully entitled to withdraw from the study at any time without any need to give a reason and without incurring any displeasure or disadvantage.

**Further information:** Dr Helen Clayson can be contacted on 01229 889836(answer-phone) or at St Mary's Hospice, Ford Park, Ulverston, Tel 01229 580305,

Alternatively please feel able to discuss this with your Macmillan or Lung Specialist nurse who will be fully informed about this study

**Thank you for your consideration of this research project**

Dr Helen Clayson

## Appendix 2: CONSENT FORM (Interviewee's copy)

Dr. Helen Clayson

MB.BS., F.R.C.G.P., F.R.C.P., D.R.C.O.G.

The Surgery  
Askew Gate  
Kirkby-in-Furness  
Cumbria LA17 7TE  
Tel: (01229) 889247  
Fax: (01229) 889097  
..

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### CONSENT FORM (Interviewee's copy)

**Study title: Palliative care in mesothelioma: What are the needs of patients and their families?**

Name:

d.o.b.

Address:

**I confirm that I have read and understood the information leaflet regarding this study and I am willing to be interviewed at home by Dr Helen Clayson. I understand that I can withdraw from the study at any time and that participation or non-participation will not have any effect on my treatment or management.**

Signature of interviewee:

Date:

Countersignature( Macmillan nurse or researcher):

Date:

## Appendix 3: GP letter re patient recruitment

Dr. Helen Clayson

MB.BS, F.R.C.G.P., F.R.C.P., D.R.C.O.G.

The Surgery  
Askew Gate  
Kirkby-in-Furness  
Cumbria LA17 7TE  
Tel: (01229) 889247  
Fax: (01229) 889097

---

Dear Doctor,

Re:

I am just writing to inform you that your patient has agreed to be interviewed by me as part of a research project entitled '**Palliative care in mesothelioma: What are the needs of patients and their families?**'

The aim of the study is to explore the meaning and experience of mesothelioma to patients and their families and to then use this data to develop recommendations regarding the provision of services in Primary Care and Community settings.

The interview will be at the patient's home and should take about an hour on

.....

A full research protocol is available if you would like to see it.

If you wish any further information please contact me or Joanne Brodie, Research Secretary, at the Trent Palliative Care Centre on 0114 262 0174.

Yours sincerely,

Helen Clayson

Honorary research Fellow, University of Sheffield

## **Appendix 4: PALLIATIVE CARE IN MESOTHELIOMA: PATIENT INTERVIEW SCHEDULE**

### **1. Personal history**

Eg : can you tell me about your family background and then your work history?

### **2. The disease**

Eg: Can you tell me about the start of this illness?

Eg: How was the diagnosis made?

Eg: What symptoms are you experiencing?

### **3. Asbestos exposure**

Eg: What do you believe about the cause of this illness?

Eg: Were you aware of the risks of asbestos at any time?

Eg: How did you learn about asbestos risks?

### **4. Impact of the disease and coping strategies**

Eg: Can you describe how you learnt of the diagnosis?

Eg: Can you describe your reaction?

Eg: How have you dealt with those feelings?

Eg: Who or what has been helpful?

Eg: What effects has this had on your family?

### **5. Are there any other matters that you would like to raise?**



## **Appendix 5: Advertisement published in local newspapers in Barrow, Leeds and Doncaster to recruit bereaved relatives.**

### MESOTHELIOMA RESEARCH PROJECT

Dr Helen Clayson, Research Fellow, University of Sheffield, is currently studying the impact of mesothelioma, the asbestos-related cancer, on patients' families. In order to understand the effects on families she is arranging a series of small local discussion groups of close relatives of people who have died with mesothelioma in the Leeds and Doncaster areas between 1<sup>st</sup> January 2000 and 1<sup>st</sup> January 2003. If you are a bereaved relative or partner and feel that you might be able to contribute to this study please request an information leaflet, all enquiries and any participation in a group will be completely confidential.

Please contact Joanne Brodie at the Trent Palliative Care Centre : 0114 262 0174 ext 25.

## **Appendix 6: Recruitment letter : Bereaved relatives, Leeds**

Printed on headed notepaper from Trent Palliative Care Centre, University of Sheffield.

May 2003

Dear

**Re: Discussion groups for bereaved relatives of mesothelioma patients.**

I am pleased to enclose an information leaflet about my research project entitled 'Palliative Care in Mesothelioma what are the needs of patients and their families'?

Once you have read it, if you are willing to take part in a discussion group, please sign the consent form and return it to me in the FREEPOST envelope.

If you need any further information please contact Joanne Brodie, research secretary: tel 0114 2620174 extension 25

Thank you for your interest and help

Yours sincerely

Helen Clayson  
Honorary Research Fellow,  
University of Sheffield.

## **Appendix 7: INFORMATION LEAFLET FOR BEREAVED RELATIVES / MAIN CARERS (LEEDS)**

**You are being invited to take part in a RESEARCH study.** Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives and your GP if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

### **Research title: Palliative care in mesothelioma: what are the needs of patients and their families?**

#### **What is the purpose of this study?**

This study is exploring the impact of mesothelioma on patients and their families. We know that understanding a disease from the patients' perspective can lead to significant improvements in the way in which health services are provided and hope that this study will help mesothelioma patients and their families in future. This part of the study will take 12 months.

#### **The researcher**

The study is being carried out by Dr Helen Clayson who is a GP and Palliative Care doctor currently working with the Trent Palliative Care Centre, University of Sheffield. Her particular interest in mesothelioma developed after being involved in the care of patients with this disease from the shipyard town of Barrow-in-Furness. The research done to date mainly concentrates on trying to find an effective treatment for the disease, there is very little written from the perspective of the patient and his/her family.

#### **Why have I been chosen?**

This part of the study is designed to examine the impact of caring for someone who has had mesothelioma. You are invited to take part in a small discussion group of bereaved relatives or main carers of mesothelioma patients that will be led by Dr Clayson. Each group will consist of 5 or 6 bereaved relatives of mesothelioma patients who died between 1.1.2001 and 1.1.2003 in the Leeds area, the researcher, Dr Clayson who will lead the group, and a research assistant.

**Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form (enclosed). If you decide to take part, you are still free to withdraw at any time and without giving a reason. This will not incur any displeasure or disadvantage

**What will it involve?**

You are invited to contribute to a discussion meeting with 5 or 6 other bereaved relatives from the Leeds area. Dr Clayson will lead the discussion which will cover the following areas: the time before the diagnosis, the impact of the diagnosis, coping with the illness, the effect on the family and your experience of the services provided to your relative and to you. You will also be given the opportunity to raise any other issues that you feel are important. A research assistant will also be present to help with note-taking and the discussion will be recorded.

**When and where ?**

The groups will be held in a convenient central location in Leeds, light refreshments will be provided and transport will be provided or, alternatively, a token payment of £5 towards expenses will be offered to anyone providing their own transport.

**NB** In order to cover a fairly recent experience the group members need to be relatives or main carers of people who have died from mesothelioma between 1<sup>st</sup> January 2001 and 1<sup>st</sup> January 2003.

**Are there any risks ?**

Some people may find that talking about the final illness of a loved one may be distressing, others may find it helpful. The researcher, as a GP, has a lot of experience of people who are grieving and the research assistant will also have experience in this area and be available for help if necessary. A leaflet giving details of helpful agencies and organisations for bereaved people will be available at the discussion meeting.

**Are there any benefits of taking part?**

There is no direct benefit to you if you do decide to take part in a discussion group but it is hoped that this research will lead to improvements in our understanding of the impact of the disease and also to improvements in the ways in which services are provided to patients with mesothelioma and their families. The discussion will also

provide you with the opportunity to raise any important issues that you have as a result of your experience caring for a close relative with mesothelioma.

**Will it be confidential?**

All information provided by you or about you will be kept strictly confidential. The researcher will comply with all the requirements of the Data Protection Act. Your name, address or any other details by which you could be identified will not be disclosed to any other party by the researcher. The researcher will destroy all tape-recordings at the end of the study.

**What will happen to the results of this study?**

The results of the study will be written up as a postgraduate degree and will also be published in professional journals. The researcher will ask each group at the end of the discussion if there are any parts of the discussion that they would not wish to be published, participants names will not be used in any articles. Publication of articles relating to the study is likely to start in 2003.

**Funding**

The study is being funded by a grant from the Scientific Foundation Board of the Royal College of General Practitioners.

**If you would like to take part** in a discussion group you will need to sign the consent form which is attached and return it in the FREEPOST envelope. A copy of the consent form will be given to you for you to keep.

**If you would like more information** regarding the study please ring the Research Secretary, Joanne Brodie at the Trent Palliative Care Centre on 0114 262 0174, extension 25 and she will make arrangements for the researcher to contact you.

**Thank you** for your interest and for taking time to read this information sheet and also thank you if you do decide to take part in the discussion group.

Dr Helen Clayson  
Honorary Research Fellow  
University of Sheffield.

# Appendix 8: Leeds focus group consent form

Centre Number: Leeds

Study Number:

Patient identification number for this study:

## CONSENT FORM FOR RESEARCH STUDY

Title of Project: **Palliative Care in Mesothelioma** - Focus groups, Leeds

Name of researcher: **Dr Helen Clayson**

Please tick to confirm

- I have read the information sheet for the above study
- I have had the opportunity to ask questions about the study, and to discuss it with family and friends
- I understand the purpose of the study and how I will be involved
- I understand and accept that if I take part in this study I will not gain any direct personal benefit from it
- I understand that all information collected in the study will be held in confidence and that if it is presented or published all my
- personal details will be removed.

I confirm that I will be taking part in this study of my own free will, and I understand that I may withdraw from it at any time and for any reason without my medical care or my legal rights being affected.

I agree to take part in the above study.

**Signature:**

**Date:**

**Countersigned:**

**Date:**

- (person taking consent)

**Researcher if different from above:**

**Date:**

## APPENDIX 9: FOCUS GROUP SCHEDULE

### 1. The time before the diagnosis

Eg: Was this a worrying time for you?  
Expand/clarify

Eg: Were you aware of there being a high risk of mesothelioma? “

Eg: How informed were you about the situation? “

### 2. The diagnosis

Eg: How were you informed of the diagnosis?

Eg: Could this have been handled better? “

Eg: How much did you understand at that time?

Eg: Can you describe your feelings at that time? “

Eg: How did this affect your relative?

Eg: Who informed other family members?

Eg: What was the impact on the family? “

### 3. Coping

Eg: Who or what helped you to cope? “

Eg: Did anything or anyone hinder your efforts?

Eg: Was coping difficult? “

Eg: What might have improved things for you?

Eg: How did the illness affect your social/family/marital life?

### 4. The final stage

Eg: Were you prepared? Expand/clarify

Eg: Could anything have improved the situation for you at that time? “

Eg: Were you aware of the procedures after the death?

Eg: If not, how and by whom should this information be given?

Eg: Was your relative aware of the procedures that would be necessary after his/her death?

Eg: What are your feelings about this? “

5. Do you have any other important matters to raise that would improve the care of mesothelioma patients and their families?

# Appendix 10: Invitation to healthcare professionals

*Header: my surgery or TPCC, University of Sheffield*

Dear Colleague,

Re research project: Palliative care in Mesothelioma – What are the needs of patients and their families?

I am writing to request your assistance with my study. In order to answer the research question I am using both quantitative and qualitative methods including interviews with Mesothelioma patients, focus groups of bereaved relatives of Mesothelioma patients, interviews with 'stakeholders' ie professionals involved in the care of Mesothelioma patients and also reviewing the hospital and GP case notes of patients who died with Mesothelioma in the Furness area between 1997 and 2001.

I would very much appreciate being able to interview you in view of your experience with these patients. The interview would take approximately 30 minutes and would be arranged at your convenience. For the purpose of the study the interview would be recorded onto mini-disc then transcribed by me .I understand that health care professionals may have particular concerns regarding confidentiality and I can assure you that the study complies with the Data Protection Act.

A full research proposal can readily be forwarded to you if you wish.

I enclose a reply slip and sae and I do hope that you will be willing to contribute to this study.

Yours sincerely

Dr Helen Clayson  
-----

I do/do not agree to being interviewed by Dr Helen Clayson [delete as necessary]

The most convenient time/s would be:

Signed:

Please print name clearly:



## **Appendix 11: INTERVIEW SCHEDULE – STAKEHOLDERS**

### 1) CONTACT WITH PATIENTS

Can you describe your contact with mesothelioma patients?

What do you see as the main issues in caring for this group of people?

Do you feel that this group of patients has any particular features compared with lung cancer patients?

### 2) CONTACT WITH BEREAVED RELATIVES

Do you have any contact with bereaved relatives of mesothelioma patients?

If yes, has this influenced your practice in any way?

If yes, do you have a policy or routine for dealing with the bereaved relatives?

Do you have any suggestions about the care of bereaved relatives?

### 3) BEST PRACTICE

How would you describe 'best practice' in the care of mesothelioma patients?

Are there any developments that you would like to see in this area?

Do you perceive any difficulties in achieving 'best practice'?

If yes, are there any factors which could be overcome to achieve the desired changes?

Can you identify any other people or agencies that you feel should have more involvement in the care of mesothelioma patients or their families?

### 4) CLINICAL TRIALS

How do you feel about clinical trials in mesothelioma?

Does this affect your practice with regard to recruitment to trials?

Does the issue of trials pose any ethical dilemma for you?

### 5) AOB

Are there any other issues re the care of mesothelioma patients or their families that you would like to raise?

## Appendix 12: DATA ENTRY PROFORMA: MESOTHELIOMA NOTES SURVEY

### A : Demography

Unique identifier      
 DOBd   m   y    
 Gender  M/F  
 Marital status  M/S/W/D/Cohabiting  
 Post Code        
 Occupation ...   
 GP Code          
 Asbestos exposure   
 Dates of exposure  m   y  ,  m   y    
 m   y  ,  m   y    
 m   y  ,  m   y    
  
 Occupation/s when exposed ...   
  
 Smoking status  Never/Ever smoked  
 Number currently smoked/day    
 Date smoking ceased  d   m   y

### B Disease presentation

Onset of symptoms  d   m   y    
 Date of presentation  d   m   y    
 to secondary care   
 Mode of presentation ...

### C Investigations (enter no of times for each category and dates)

CXR  Dates:   
 Pleural aspiration  Dates:   
 Biopsy:  Needle  Dates:   
 Open  Dates:  VATS  Dates:   
 Biopsy site:  Pleural  Lung  Peritoneal   
 Metastasis

CT scan  
MRI scan  
22(a) Other

Other   
 Dates:  
 Dates:

#### D Confirmation of diagnosis

Histology:  
Histology obtained by:  
...  
Date of diagnosis  
Date patient informed  
Patient informed by ...

Epith  Sarc  Mixed  Other ...  
Pleural fluid  Biopsy  PM  Other  
d   m   y    
d   m   y

#### E Recorded symptoms

Pain   
Dyspnoea   
Weight loss   
Depression   
Anxiety   
Emotional distress   
Psychological   
Social problems   
Other major symptoms ...

#### F Therapeutic interventions (enter no of times for each category nos 37 – 40)

Pleural aspiration   Dates: ...  
Pleurodesis   Dates: ...  
Debulking   Dates: ...  
Paracentesis   Dates: ...

Pain relief techniques:

Tens  Dates: ... Intercostal  Dates: ... Paravertebral  Dates: ...  
Interpleural  Dates: ... Epidural  Dates: ... Intrathecal  Dates: ...  
PCC  Dates: ... Other ...

Palliative chemo  Dates: ...  
Chemo trial  Dates: ...

DXT  Dates:...

Curative surgery

Dates:...

Palliative surgery

Dates:...

Immunological Rx

Dates:...

Palliative drug therapy:

(a) Opiates

Types of medication:

Date of 1<sup>st</sup> ... :

Max daily dose:

(b) Adjuvant analgesics

Types of medication:

Date of 1<sup>st</sup> ... :

Max daily dose:

(c) Anti emetics

Types of medication:

Date of 1<sup>st</sup> ...:

Max daily dose:

(d) Anxiolytics

Types of medication:

Date of 1<sup>st</sup> ...:

Max daily dose:

(e) Anti depressants

Types of medication:

Date of 1<sup>st</sup> ...:

Max daily dose:

(f) Other

Types of medication:

Date of 1<sup>st</sup> ...:

Max daily dose:

G. Primary care episodes (12 months prior to death)

Consultations:

Date	Health Professional Consulted	Reason	Action

**H. Secondary care episodes**

**50: OPD attendances**

Date	Hospital	Department	Reason

**Admissions to hospital**

<u>Date</u>	<u>Reason</u>	<u>Hospital</u>	<u>Dept</u>

**Admissions to Hospice**

<u>Date</u>	<u>Reason</u>

Day Care Yes/No/Not recorded

I. Referrals

- Respiratory Physician
- Oncologist
- Palliative Care Physician
- Radiotherapist
- Thoracic Surgeon
- 58(a) Pain consultant
- Lung Cancer Nurse
- Macmillan Nurse
- Psychiatrist
- Psychologist
- Social Worker
- Support organisation
- 65 Other/s ...

J. Co-morbidity

66 Other significant diagnoses

<u>Date diagnosed</u>	<u>Condition</u>

K. Details of death

- 67 Date d  m  y
- 68 Place Home  Hospital  Hospice  Other ...
- 69 Referred to Coroner
- 70 Date of PM d  m  y
- 71 Date of Inquest d  m  y
- 72 Outcome of Inquest ...
- 73 Details on death certificate:  
1(a):                      1(b):                      11:
- 74 Mode of death:

## Appendix 13: Oral presentations and publications related to the study

### Presentations

7.3.2007

Palliative aspects of mesothelioma care. *Improving outcomes in Mesothelioma: The National Mesothelioma Framework*. Leeds.

3.3.2007

Active symptom control and psychological aspects. *European School of Oncology, Mesothelioma Conference*. Brussels.

20.10.2006

Patients' and carers' experience of mesothelioma. *Supportive care satellite symposium, 8th International Meeting of the International Mesothelioma Interest Group*. Chicago.

25.5.2006

Experiencing mesothelioma: Palliative care needs of patients and their families. *European Association of Palliative Care Research Forum*, Venice.

11.5.2006

Mesothelioma from the patient's perspective. *Clydeside Action on Asbestos Mesothelioma conference*. London School of Hygiene and Tropical Medicine.

8.5.2006

Palliative care in mesothelioma. *Lancashire and S Cumbria Cancer Services Network Mesothelioma Study Day*. Preston.

5.4.2006

Palliative care service issues in mesothelioma. *Palliative Care Congress*. Sheffield.

10.6.2005

Mesothelioma and palliative care. *Cancer Research Away Day*. Sheffield.

18.5.2005

End-of-life care in mesothelioma. *Mesothelioma: the silent epidemic*. British Museum, London.

9.3.2005

End-of-life care. *Mesothelioma Summit*. BMA House, London.

25.6.2004

Mesothelioma from the patient's perspective. *7<sup>th</sup> International Conference of the International Mesothelioma Interest Group*. Brescia, Italy.

23.3.2004

Palliative care research in mesothelioma: The experience of patients and their families. *Mesothelioma: The silent epidemic*. Newcastle.



31.10.2003

Palliative care in mesothelioma: What are the needs of patients and their families. *National Lung Cancer Forum for Nurses Conference*. Edinburgh.

16.1 2003

Mesothelioma: The search for effective treatments.

And

Palliative care in mesothelioma: What are the needs of patients and their families?

*Mesothelioma Network Nurses Study Day*. Sheffield

22.3.2002

Palliative care in mesothelioma: What are the issues? *Mesothelioma: the silent epidemic*. Lakeside, Cumbria.

11.7.2002

Palliative care in mesothelioma. *Sheffield Palliative Care Studies Group Research meeting*. Sheffield.

22.11.2001

Palliative care in mesothelioma: What are the issues? *Lung Cancer Research Group*, Leeds General Infirmary. Leeds.

## **Publications**

Ahmedzai S A, Clayson H (2006) Palliative Care in Mesothelioma. In: O'Byrne K and Rusch V (eds) *Malignant Pleural Mesothelioma*. Oxford: Oxford University Press, 402-433

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