

# Exploring the patient's experience during the first three months following a diagnosis of Malignant Pleural Mesothelioma

A Project Funded by the Surrey, West Sussex and Hampshire Cancer Network

Dr Anne Arber

Lesley Spencer

Susan Quirin

Therese Partridge-James

Samantha Russell

Alan Parker

Cathy Brockbanks

Louisa Dennis

Collette Davies

Dr Paul Murray

**Final Report January 2010**

**Address for Correspondence:**

Faculty of Health and Medical Sciences,

Duke of Kent Building

Stag Hill Campus

University of Surrey

Guildford

[A.Arber@surrey.ac.uk](mailto:A.Arber@surrey.ac.uk)

# Executive Summary

This report explores how patients with malignant pleural mesothelioma (MPM) cope during the first three months following diagnosis. With the incidence of MPM rising and expected to peak between 2010 and 2015 it is timely to produce research evidence related to the patient's experience following a diagnosis and to explore how patients are supported in the early phase of this devastating disease. This study is concerned with how patients cope with this diagnosis from an emotional perspective; how they navigate their care pathway, manage debilitating symptoms such as pain, breathlessness and functional in-capacity and how they cope with living with an illness that has a poor prognosis.

The study uses a grounded theory methodology involving in-depth narrative interviews with 10 people diagnosed with MPM in the last three months, from two hospital trusts in the UK. Data was analysed using the constant comparative method to identify common categories and then themes.

A key theme that emerged from the data was the feeling of hopelessness associated with MPM in that it is 'all bad news' which was associated with participants experiencing anxiety, worry, emotional distress and using coping strategies such as avoidance or a 'head in the sand' approach. The findings indicate that participants had many concerns and worries about the future and experienced many losses including loss of social activities and emotional distress. Participants describe how they experience a loss of control of their lives; have worries about the speed of their physical deterioration and death, and the potential for loss of their independence. Participants coped by restricting their physical activities to avoid breathlessness. Some found it difficult to pace their activities and became easily exhausted and breathless on exertion.

Accepting treatment with chemotherapy was a difficult and considered decision due to the all the 'bad news' related to MPM, the knowledge of a poor prognosis, the perceived limited efficacy for chemotherapy treatment and the experience of side effects following treatment. A few participants were not sure why they were not

offered chemotherapy and thought this was due to their disease being advanced. None of the participants suffered from intractable pain at this early stage of the disease. Many suffered loss of appetite and weight loss. At least half of the participants were distressed by symptoms associated with profuse sweating, often at night. Although they did access specialist palliative care this was usually when they were not having treatment or had decided to stop treatment. Participants found it difficult to cope when they moved to different hospitals for investigations and treatment. They felt unsure about who was in charge of their care at this time. They did not report an understanding of the multidisciplinary nature of their care.

The recommendations following this study are:

1. Proactive management and early identification of breathlessness as a symptom. A local breathlessness management course would enhance the patient's ability to cope with this debilitating symptom.
2. Patients should be offered information and advice on Pacing at diagnosis. Together with this there is a need to include information on the local multi disciplinary team and locality of treatments in order to provide clarity on the care pathway.
3. There is a need to ensure that the role of the Key Worker (in this instance the specialist nurse) is embedded into local practice, as patients and carers found this role to be beneficial and supportive. Innovative and flexible ways of providing care should be considered.
4. Participants who were referred to palliative care found this helpful. The Clinical Nurse Specialists (CNS) were able to offer supportive care and the study demonstrates that patients did feel supported but at the risk of leaving the need for specialist palliative care unmet.
5. It is recommended that early referral to the community palliative care team is considered and that there is close liaison between specialist palliative care and the CNSs in order to optimize total support for the patient.
6. This study supports the National Advanced Communication Skills course as being mandatory for specialist nurses and doctors.
7. Clarity is needed around the communication of treatment decisions, particularly around chemotherapy. Oncologists may need to prioritise information about treatment

as it appears that a lack of understanding by the patient, coupled with the negativity around the disease and prognosis makes it hard for patients to accept chemotherapy.

8. Referral to a Dietician is necessary at diagnosis as well as on-going nutritional assessment, as the majority of patients suffered weight loss and anorexia.

9. Further investigation is needed to find effective ways of managing day/night sweats as 50% of patients found this to be a distressing symptom. It is recommended that this symptom is assessed by the MDT and practical advice and support offered.

10. All patients should be made aware of their local asbestos support group.

11. Consider setting up a local support group for patients with Mesothelioma and Lung Cancer to include professionals, patients, carers and network partnership support.

# Acknowledgements

We wish to thank all the patients and carers who participated in the research; they generously gave of their time and freely shared their experiences. For this we are very grateful.

The study was generously funded by Surrey, West Sussex and Hampshire Cancer Network, Service Improvement Grant.

This study, its completion and findings are as a result of lecturers, clinicians and a carer working collaboratively together throughout the whole process as part of a project team. The team would like to extend thanks to all those who have supported them in their efforts to understand this disease from the patient perspective.

# Table of Contents

<b>Executive Summary</b> .....	<b>2</b>
<b>Acknowledgements</b> .....	<b>5</b>
<b>Table of Contents</b> .....	<b>6</b>
<b>Introduction</b> .....	<b>7</b>
<b>Rationale for the study</b> .....	<b>9</b>
Research questions.....	9
Methods .....	9
Data Analysis.....	10
Sample .....	10
<b>Findings</b> .....	<b>11</b>
Coming to terms with the diagnosis: ‘it’s all bad news’ .....	11
Prognosis and Uncertainty .....	13
Experience of Symptoms .....	16
Coping Strategies.....	19
Negotiating the care pathway.....	21
Treatment options .....	22
Contact with asbestos: Legal and Financial Issues .....	23
<b>Discussion</b> .....	<b>26</b>
What are the main symptoms experienced by patients and what strategies do they use to manage symptoms? .....	26
To what extent are patients quality of life affected during the first three months following diagnosis? .....	28
How do patients experience their care pathway? .....	29
How and when do patients access palliative care services and other agencies? .....	30
Limitations of the study .....	31
<b>Recommendations following the study</b> .....	<b>32</b>
<b>References</b> .....	<b>35</b>
<b>Appendix 1</b> .....	<b>37</b>
Topic Guide for Patient Interviews.....	37
<b>Appendix 2</b> .....	<b>39</b>
Table 1 Demographic Information and type of mesothelioma.....	39
<b>Appendix 3</b> .....	<b>40</b>
Table 2 Symptoms experienced .....	40

# Introduction

Malignant pleural mesothelioma (MPM) is a challenging disease as it can be difficult to diagnose and following diagnosis patients generally have a short life expectancy. Alongside this there are quality of life issues related to emotional distress, functional status, symptoms and complicated medico-legal and financial concerns to be faced. There is a paucity of research evidence to produce evidence based guidance related to patients with MPM. The Mesothelioma Framework has been developed by a professional consensus related to good practice in the delivery of services for those with MPM. This consensus recommends a key worker system for all patients, to facilitate referrals and to provide information. The consensus recommends that all cases should be managed by a specialist multidisciplinary team (DOH 2007). It is not clear to what extent these guidelines are effective in practice from the perspective of the patient. With the incidence of MPM rising and expected to peak between 2010 and 2015 it is timely to produce research evidence related to the patient's experience following a diagnosis of MPM and to investigate how patients are supported in the early phase of the disease. This study is concerned with the patient's experience in the first three months following diagnosis.

MPM is a rare cancer with a rising incidence associated with asbestos exposure although a small proportion of cases are unrelated to asbestos exposure (Yates et al 1997). The clinical features associated with this disease are chest pain, dyspnoea, breathlessness as well as pleural effusion. The disease is more likely to occur in late middle age with a long latent period between exposure to asbestos and the development of the disease; with a mean latency of 40 years. The disease has a late presentation and there can be problems in achieving a diagnosis in the early stages. The incidence of mesothelioma among UK males is reported as 1,942 and for females 385 (Cancer Research UK 2009). It is predicted that male deaths from mesothelioma will peak in 2020 with between 2,700 and 3,300 deaths (Peto et al 1995). The groups at most risk of the disease are plumbers, gas fitters, electricians and carpenters. The worst affected group is men born in the UK in the 1940s. Most of the asbestos used in buildings was imported into Britain during 1960-1980 and many workers in the building and demolition industries may be exposed (Peto et al 1995). Asbestos is still in many buildings, used as insulation and exposure may occur unknowingly. The disease is invariably fatal with many people dying within a year of diagnosis with

typical survival of only 7-10 months (Yates et al 1997). There may be some difficulty in obtaining a diagnosis causing significant delay and intense worry for patients and their families. It can be difficult to confirm the diagnosis as negative cytological results do not exclude mesothelioma. Diagnosis is dependent on evidence of chest wall pain, pleural thickening and pleural effusion. It is important for health care professionals to be aware of the possibility of delay in receiving a diagnosis as it is highly distressing and upsetting when it occurs (Hughes 2006). So far treatment has not achieved improvement in survival and palliative and supportive care is important to sustaining a good quality of life (QOL) with effective control of symptoms and support for patient and carers.

The evidence that does exist suggests that patients and carers may have many unmet needs in relation to maintaining an acceptable quality of life when mesothelioma is diagnosed; although there is a limited amount of research in this area (Hughes and Arber 2008, Lee et al 2008, Hawley et al 2004). Significantly psychosocial distress is reported as a serious issue for patients and families (BLF 2009, Clayson 2007).

There is more research related to the experience of lung cancer, in particular managing the problem of breathlessness. However there are some differences in experiences between patients who have lung cancer and those with mesothelioma. For example patients with mesothelioma did not report experiencing the feeling of stigma associated with lung cancer and smoking and therefore they expressed relief that mesothelioma was not related to smoking (Corner et al 2006, Hughes 2006, Chapple et al 2004). The typical presentation of mesothelioma is chest pain which can be mistaken for cardiac symptoms (Hughes 2006, Krishnasamy et al 2001) and or dyspnoea. The pain may involve a heavy feeling, aching in the shoulder and arm, chest wall and upper abdomen. Neuropathic components can be a feature due to nerve involvement (British Thoracic Society Standards of Care Committee 2001). Unlike lung cancer distant metastases are unusual and if they do occur are likely to occur late, with the disease progressing by local extension. However there can be pericardial involvement and weight loss is prominent. The disease trajectory may be rapid or there may be periods of stability with some patients surviving over a period of more than 3 years. This group are more likely to have the epithelioid type of mesothelioma.



# **Rationale for the study**

The Surrey, West Sussex and Hampshire (SWSH) Cancer Network in collaboration with the University of Surrey are keen to explore the patient's experience following a diagnosis of MPM. Clinical experience concurs with the limited evidence available and suggests that patients and their carers have many unmet needs due to a rapidly changing situation with physical decline and the associated psychosocial and emotional consequences. Our aim is to explore these issues in more depth from a patient perspective. To identify how patients cope during the first three months of the disease and to explore the strategies and services they find helpful to enable them to maintain an acceptable quality of life. Many of the issues experienced by patients such as emotional distress, managing symptoms such as pain, breathlessness and functional incapacity are very important in the early stage of the disease as patients and families develop skills in coping and managing on a day to day basis. We are interested in the components of help and support available to people with MPM and to identify gaps in services and to make recommendations for service development, education and liaison across professional and disciplinary boundaries.

## ***Research questions***

- What are the main symptoms experienced by patients and what strategies do they use to manage symptoms?
- How do patients experience their care pathway?
- How and when do patients access palliative care services and other agencies e.g. social care, physiotherapy, occupational therapy, social work?
- To what extent are patients QOL affected during the first three months following diagnosis?

## **Methods**

The research is designed as a grounded theory study of 10 patients diagnosed with MPM within the last three months. The study uses narrative interviews to explore the patient's experience. The interviews lasted between 40 minutes and 90 minutes. Eight interviews were audio recorded in the patient's home. One interview was carried out in the hospital out-patient department and the patient did not wish for the

interview to be audio recorded so hand written notes were made by the researcher, with the patient's permission. One interview was carried out in a hospital ward when the patient was admitted with a pleural effusion. Five patients were interviewed in the presence of their partner. The interviews were in depth, yet loosely structured to allow the breadth and variety of issues from the patient perspective to emerge (See appendix 1 for topic guide). In keeping with the grounded theory approach the structure of the interviews became more focussed as the study progressed.

### ***Data Analysis***

The data was analysed using a grounded theory approach (Glaser and Strauss 1967). The constant comparative method was used for analysis of the data with text coded and compared for similarities and differences until substantive categories and themes emerged.

### **Sample**

This is a purposive sample of ten patients recruited from two services in the SWSH Cancer Network (Appendix 2). The sample consists of those patients who have been diagnosed with MPM within the past three months and includes those having active treatment and palliative/supportive care. The research proposal was approved by the National Research Ethics Service, the Hospital Trust's Research and Development Committee and the University of Surrey Ethics Committee.

# Findings

Ten patients, eight men and two women were interviewed from two NHS trusts in the South of England. The average age of participants was 70 years. All participants report experiencing high levels of uncertainty and loss of control and many had concerns about the future. All were worried about the speed of their physical deterioration although many reported feeling quite well at the moment. They all experienced more than one symptom, as well as emotional distress and worry, which reduced their quality of life. All the participants found it difficult to cope with their diagnosis due to all the negative information and ‘bad news’ around mesothelioma.

## ***Coming to terms with the diagnosis: ‘it’s all bad news’***

In the first three months following a diagnosis of MPM participant’s describe how they struggle to come to terms with their diagnosis and the emotional implications. Mr F is shattered by the news of his diagnosis. He says how ‘*all of a sudden in that short period of time it’s sort of taken away from you*’. Participants describe a range of losses that they are experiencing as well as the emotional reactions to the diagnosis including shock, disbelief, anger and resignation. For Mr H he is reluctant to find out more about mesothelioma as he says ‘*it’s all bad news isn’t it?*’ The feeling of hopelessness around the diagnosis is also reported by carers in the small study by Lee et al (2008). In Clayson’s (2007) study of 15 patients with mesothelioma she reports how patients perceive a hopeless message of an incurable disease with few treatments on offer.

The participants describe the speed at which the investigations are carried out and the diagnosis made. They also say how difficult it is to take on board the enormity of what they are hearing and to cope with the anxiety that such a diagnosis engenders:

*You haven’t got enough time I think to come to terms with everything, what did she say, did she say that? (Mr H)*

Mr H reports difficulty remembering what he has been told and the accuracy of what he remembers. Therefore the shock is coupled with the speed with which everything is moving and this seems to lead to a feeling of losing control. Like Mr H, Mr E also refers to the fast pace at which everything is moving ‘*everything was done so quickly and you don’t really know what’s hit you*’.

A number of patients felt totally unprepared for a diagnosis of MPM. Mrs G and her husband Mr G describe their total shock at hearing Mrs G had a cancer:

- Mr G: When we went up there we was all still like this you know, and he said, well I'm afraid I've got bad news for you, you've got a tumour. And we said, what, cancer? And he said, yeh, afraid so. I mean, talking about knock the wind out of your sails.*
- Mrs G: That was such a shock, I didn't know what to say.*
- Mr G: And after that you can't comprehend what they're talking about.*
- Mrs G I wanted to ask such a lot of questions, but I just couldn't think of them.*

Mr and Mrs G felt absolutely devastated by the diagnosis. They found it difficult to comprehend what they were being told and felt unable to ask any questions at this consultation due to experiencing shock. Mrs G had many questions to ask. In particular Mrs G was concerned with the stage of her disease and what the future holds for her. She needed time to understand and come to terms with what she had been told. Her husband was also very anxious and worried. Both needed to talk about their experiences and their distress during the interview and were trying to make sense of their experience.

For one patient, Mr E, the realisation of how 'ill' he was came when he was being informed with his wife of the benefits they were entitled to:

*Now what really hit the pair of us was when Jane said, right well you, I must get on because you are entitled to this Attendance Allowance and this, all these allowances, and that, and I looked at Mary and she looked at me, and basically we both burst into tears. He's ill, that was when it suddenly hit you when they said you are going to get all these bits and pieces and she said, I don't want any money, she said I love him, I'll look after him. But, ehm, that really did hit, that you suddenly realised, crickey I'm ill. (Mr E)*

It is difficult for patients to understand their condition as firstly they generally are not aware of a cancer called mesothelioma and secondly many people have already adapted their life to coping with breathlessness. For example Mr E had stopped playing bowls some time ago, long before his diagnosis, due to his shortness of breath and tiredness.

Participants are completely shattered when hearing about their diagnosis and poor prognosis and find this difficult to comprehend. They experience a great deal of

anxiety and emotional distress and this is made worse by the hopelessness associated with MPM in that it is ‘all bad news’.

## **Prognosis and Uncertainty**

All participants were coping with a high level of uncertainty in relation to their future. Many people in the study were not sure what the future holds and what was going to happen to them in terms of their deterioration and death. Mr D demonstrates the importance of the doctor’s non-verbal communication skills when discussing sensitive issues:

*I’d like to know how long have I got, I started talking to him [the consultant] and once he saw I wasn’t worried, he clicked, I watched his eyes. He relaxed when he could see I wasn’t worried and he said...*

Mr D describes how he talks to the doctor, reads his facial expression and eye contact and how he introduces talk of his prognosis in a way that is sensitive to the non-verbal communication of the doctor. He demonstrates to the doctor that he is not scared and wants to know his prognosis.

Mrs A describes the dread she experiences of ‘*sort of waiting, it’s almost waiting to feel worse*’. She also says ‘*Knowing that I’m going to feel worse, when am I going to feel worse?*’ She has many anxieties and questions about how she will physically deteriorate and when this will happen.

Participants are very well aware of the terminal nature of their condition. Mr and Mrs C cope with the uncertainty by trying to avoid it:

*Mrs C: We are a bit ‘head in the sand’ at the moment, I think, whilst he is feeling quite well we don’t want to go too deeply into what may be and what will be.*

And

*Mr C: It doesn’t pay to think too far down the road because that’s bad news. As you say, head in the sand.*

The dilemma for Mrs C is coping with the reality of a serious life-limiting disease when her husband is feeling ‘quite well’. One way that they manage to continue as before is by protecting themselves by avoidance of the ‘bad news’ that Mr C has a terminal illness and is going to die. Mr and Mrs C are a very close couple. Mrs C uses ‘we’ which indicates her support for her husband as they are a team. The metaphor of ‘head in the sand’ is the way they keep positive while Mr C is feeling

quite well. Therefore one of the coping strategies identified is to try to avoid looking for in-depth information about this condition. This helps them to avoid the realisation of the ‘bad news’.

Mr I had a lot of uncertainties about the future. He describes how mesothelioma is a ‘terminal disease’ and how he initially was preparing for his death:

*I mean originally I thought, well I'm not going to live more than a month...and we were preparing our, even my burial I was getting ready.*

Mr I was preparing for the worst scenario thinking that he was going to die very soon. He was planning and preparing for his death and his funeral. Also Mr I uses ‘we’ in that his wife was also preparing with him. Mr I goes on to talk about his uncertainties and struggles in relation to his life expectancy:

*I don't know what tomorrow will bring, or next month, I don't even know if I can look to Christmas....really, I don't know the speed of these things or...but I just don't know. Something might turn up, who knows.*

He has great anxieties around the speed of his disease progression and how long he can expect to live. He uses ‘I don’t know’ four times in this data extract emphasising his loss of certainty in the future whether that is tomorrow or at another date in the future. In particular he is worried about the speed of his disease progression and deterioration and can only think that something might turn up. He is at a loss about what to do with the loss of certainty in his life. Mrs G and her husband were also concerned about the future and what is going to happen as her condition deteriorates:

*Mrs G: I still, even now, I don't know what's going to..*

*Mr G: the ultimate.*

*Mrs G: the ultimate. Am I going to start feeling bad, and I going to end up the last few months..*

*Mr G: being spoon fed.*

*Mrs G: of my life being in bed, or, you know, or what? I don't know. You just don't know do you really.*

Mrs G like Mr I also uses ‘I don’t know’ which points to her loss of certainty in the future. Mr I and Mr and Mrs G understand the serious nature of having a condition like mesothelioma. Mrs G has many worries about when death (the ultimate) will occur and the process of dying (being spoon fed). In particular Mrs G is concerned and anxious about how she will be in the last few months of life- dependent on others and bed bound is what she is afraid of. She found it very distressing and frightening coping with these thoughts. She is in need of someone to talk to about her fears and worries.

Mr C talked about asking the doctor about his life expectancy:

*We asked him what was my life expectancy, he said if I did nothing three months, if I had the treatment, twelve months. So that was, I classed him as the hard man because after that we saw the chemotherapist who I think was the soft man, he said well those typically are figures that are a little bit meaningless. Some people it's less, some people it's more, he said I don't normally see people as fit as you are, so you've got that on your side.*

Mr C describes the very short prognosis he was given if he doesn't have treatment and he describes the doctor who gave him this information, following his question, as the 'hard man'. The 'soft man' the chemotherapist had a more hopeful message particularly as Mr C is fit and he may not be representative of people with this condition. Mr C describes how the message delivered about his prognosis was hard, a harsh reality in a very difficult situation. The second doctor had a more gentle approach and was able to soften the blow and allow some room for some hope. It is essential for medical staff to take care in how they deliver devastating news related to this condition as patient's hope can be taken away and this increases patient's experience of suffering. A good doctor-patient relationship that is empathetic to patients suffering can help them remain hopeful (Clayson 2007).

Participants report how they feel uncertain about returning to work as they fear the loss of having to give up work again should it get too much for them. Mrs A misses the social contacts she had at work. She was certain she needed to give up work when she felt so ill but now is missing work when she is feeling better:

*I mean in some ways I wish I was back at work. You know you've got your friends at work and we used to have a laugh all the girls and we got on so well. Ahm you sort of miss that really cause I'm just at home all the time you know and I've had agoraphobia since I was a teenager. So I find it hard to go out and that so it was just being with your friends I've got too much time now to think how I feel so you know*

The interesting issue here is how much better Mrs A is feeling. Physically she feels a lot better compared to when she first experienced breathlessness and pain. Mrs A feels isolated from her friends since she has been off work. Now that she is feeling better she misses the companionship that her work colleagues offered. She also has more time to think about her situation.

The lack of certainty and lack of control of the future is also reported by Professor Sweeney a medical doctor who describes the 'catastrophic hurt' of being diagnosed with mesothelioma (Sweeney et al 2009). Professor Sweeney was seeking a guide to

direct him and a professional to be with him in a place of great uncertainty. Clayson (2007) also found that patients experienced a loss of agency and control but this could be ameliorated by a good doctor patient relationship. Good relationships with other staff such as Clinical Nurse Specialists and Community Palliative Care nurses were also important.

### ***Experience of Symptoms***

All participants experienced a range of symptoms (Appendix 3). On average participants experienced six symptoms. Everybody experienced some degree of breathlessness on exertion and many patients felt fatigued and tired after physical activity. For many the breathlessness had improved and they felt much more comfortable since they had a pleurodesis following drainage of a pleural effusion. Only one participant does not report having a pleural effusion. Mrs A explains how much better she felt after having the pleural fluid removed:

*Going up the stairs you know (makes a breathing sound) breathless all the time ahm I came back from my friends once when it started to snow and I ran up and you know I could hardly ahm I was just awful. So that must have been but then after I had the removal of the fluid and I think I got better in myself after that being so run down that I felt a bit better then.*

Mr F really doesn't know what to expect in terms of symptoms but he does have a cough and describes 'catching his breath':

*To be truthful with you I don't really know what other symptoms I'm supposed to have, you know what I mean. I don't know. There's questions like the doctors ask me and I tell them and the only sort of symptoms I get is this, it's like a catching of the breath. I sometimes get a tight chest but I don't know quite whether I'm putting that down to ehm ...coughing ... to that. Or indigestion. Because another thing I have noticed since this has started, I do suffer with indigestion and, but what I'm doing, I'm taking artichoke tablets, you know from the...*

Mr F is feeling anxious about what to expect in terms of symptoms as he describes a tight chest and 'catching of the breath'. However Mr F is unsure about what symptoms to expect in his response 'I don't know'. Perhaps for Mr F the significance attached to symptoms is the issue. Clayson (2007) reports that uncertainty in the progress of the disease caused anxiety and the significance of symptoms was an issue for participants in her study. She suggests that the experience of symptoms such as breathlessness is an indicator to patients of the progression of their disease.



Participants make a link between their experience of physical symptoms such as breathlessness and fatigue and their subjective feelings of distress and disease progression and this is also reported by Clayson (2007).

Weight loss and anorexia was a common problem for many. Participants describe significant loss of weight from half a stone to two stone. Mr J describes a loss of interest in food as well as heartburn and indigestion, which was also reported by Mr F and Mr J. Mr H was really struggling to cook and eat. He describes how: *You tend not to want to cook and when you don't feel well, everything doubling up on you*. Mrs G also has no appetite and has lost over a stone and a half.

For Mr F the worst thing about losing weight was a feeling of self consciousness that other people would notice and know he was ill:

*Mr F: You know, but I do feel a little bit self-conscious when I go out, the fact that I know I've lost a lot of weight and the first thing it always tells is your face isn't (it).*

*Mrs F: Most people haven't noticed really.*

*Mr F: No, I don't think they have.*

*Mrs F: I've told a few.*

*Mr F: I don't think they have. But ehm... it sort of a, kind of coming to terms with it all really.*

Mr F describes how he is coming to terms with his diagnosis but feels he wants to keep his diagnosis private as far as he can.

Not all participants experience pain (Appendix 3). Those that did report pain describe mild pain such as an ache, tenderness or soreness in the chest. Mr J describes a little ache:

*I've noticed a little ache in the chest (rubbing his chest) but doesn't affect me sleeping*

Mrs A describes being left with an ache in her side that is tender and felt a pressure in her chest:

*It feels as though there is just something pressing down on you all the time.*

Mrs G describes pain that is not controlled with Paracetamol. She has now been prescribed Tramadol to help with her pain:

*the centre of the chest is painful but it's only sore to touch, but I do get pain but the pain is mostly at night, I think during the day, because you, you are talking and you are pottering about, you take no notice, it isn't pain that's there continually.*

Clayson (2007) also found that pain was not reported as a major problem for patients. She found that patients were more likely to describe discomfort rather than pain which was managed by analgesics.

Five patient's report feeling distressed when experiencing sweating particularly at night:

*Mr D: And the other thing too that I've noticed and it's causing arguments between us, is that it's almost like what I imagine the female menopause to be. I'm sweating and I'm hot.*

*Int: Is that any time or at night?*

*Mr D: No it's, if it gets warm or the heating's on or I'm, we went shopping to a big shop, Macros, last week with two friends, and I had to go out and sit in the car. They were laughing at me because I'd taken me coat off and they said they were cold, but I was sort of sweating, until I got outside, got in the colder air, sat in the car, opened all the windows and I was all right, just sitting there and it had gone.*

Sweating is a difficult problem for Mr D as his friends are laughing at him and his wife is also finding it difficult to cope with. Mr H also reports night sweats that he describes as 'horrible' and this disturbs his sleep:

*Mr H: Yeah the sweating yeah...*

*Int: and is that every night or?*

*Mr H: Three times a night I have to change.*

The day and night sweats caused a lot of distress to patients. In particular it disturbed sleep at night and the feeling of coldness was also a persistent problem for some people. The symptom of sweating is also reported by Clayson (2007) in a review of the case notes of 80 patients with mesothelioma, sweating was reported in 14 (18%) of the case notes studied. In the present study half of the participants experienced sweating.

Most of the patients were referred, investigated and diagnosed quickly after experiencing their first symptoms of breathlessness and pain apart from Mrs A (Appendix 2). Mrs A describes how she was initially investigated for cardiac problems. She reports how in March 2007 she was put on Statins for a high cholesterol level and in May 2007 she first noticed she was breathless. Her GP dismissed her worries about her pain and breathlessness as side effects of the Statins. Finally in April 2008 following a change in GP and a referral by the new GP Mrs A received her diagnosis of MPM. This experience of a late diagnosis is unusual. Only

Mr C had earlier problems associated with chest pain that he now thinks may be related to his diagnosis:

*Mr C: Well problem started, we think, two years ago, I had a chest pain and went to Accident and Emergency, and they diagnosed that I had pleurisy and the start of pneumonia. Was treated for that for a couple of weeks and then we went and saw the specialist again and that felt as if that was the end of it.*

*Mrs C: Although he did say, you've still got a small shadow on the lung but we think it's just fluid not to worry about it.*

Participant's experience a number of distressing symptoms linked to activity and exercise. One patient in particular seemed to play down his breathlessness (Mr F) even though the researcher noticed some difficulty with his breathing as she was being shown out of the house. Clayson (2007) found that some patients were reluctant to admit to the severity of symptoms.

### **Coping Strategies**

Patients describe a number of coping strategies such as trying to think positive (Mr H), taking exercise (Mr C and Mr D), not giving in to the tiredness (Mr D), planning a holiday (Mr H) and trying to live in hope (Mr C). Mr I and Mr C had heard of people who were surviving with meso 'he's been alive for two years and we've seen a case for five years'. However he says that this strategy doesn't always work as there is so much: 'negative information around having such a disease'. Mr I also uses Complementary and Alternative Medicine (CAM). Although the participants describe a number of positive coping strategies it is difficult for them to remain positive in the face of so much 'bad news' related to mesothelioma.

Mrs A has been offered a course to help with her breathing:

*I'm going to this breathing thing which they prefer you to go before it gets worse then because she says people tend to panic when they can't take a breath and the idea of this is a four week course on one afternoon a week for 4 weeks and it teaches you how to breathe in an you know try to relax when you can't breathe telling you how to relax and the best way to breathe when you find it hard to breathe and about the drugs they can give you to relax you a bit you know if you're panicking and that about breathing so I'm going on that that's in October.*

Mrs A is able to access this course as she has a palliative care referral and the course is being offered in the local Hospice. She has been visited by her community palliative care nurse who has told her about the course and is now giving her support.

Mr H is hoping he can fit in a holiday before he starts his chemotherapy treatment:

*But it looks like I've got a holiday coming up; it looks a bit more positive.*

Mr C is keen on sailing and he is hoping to get time on his boat. He also uses his informal network of friends for advice:

*Wally when he had it had to go for a second lot of treatment did a lot of exercise during the treatment and he said he didn't suffer that way then, so we thought maybe if I'm up to it I should try and at least do something.*

So Mr C is thinking of doing exercise to help his breathing and Mr D describes not giving in to his tiredness:

*We've got a big mower that I use out the back, it weighs 3cwt, like the old park keepers used to use, and the last time I used it I sort of put it away and got the smaller one out, I had to come and sit down. And I've never done that before and I suddenly thought to myself, it is affecting me, you know, but I'm trying not to, I think what you've got to be careful of, you mustn't give in to it, you know.*

Although Mr D doesn't want to give in to his tiredness he describes 'good days and bad days' and 'if I have a late night, if I have a late night I'm affected the following day'. Despite describing himself as feeling well the physical changes that Mr D has noticed means he can't ignore his feelings of tiredness:

*Because I've got this, I have to go out with Rose or something to make me slow down because I don't and then I suddenly get uncomfortable, so I am still trying to go at my own rate. I've got to slow down, yeh.*

Mr D is finding it difficult to pace his activities. He easily exhausts himself.

Mr E describes how he accepts the changes that this illness brings and knows that he needs to slow down. However he still tries to push himself to walk as far as he can:

*It's going to slow you more and more down eventually, ehm, you just try and stop the eventually from coming too soon. So you work yourself, you know, walk as far as you really can and ehm just leave it at that, you know, hope for the best.*

Many participants are grieving the loss of previously taken for granted activities such as playing golf a game Mr F loves and having to give this up is very distressing:

*and all of a sudden in that short period of time it's sort of taken away from you then you sort of, it's like golf, I love golf, at the moment I'm never going to play golf again unless, unless the chemotherapy or something happens that I can be able to do that, but I know, that's only a small thing really but that's ehm..*

Only one participant mentioned using CAMs. Mr I is receiving an herbal and dietary therapy that he finds beneficial alongside his chemotherapy. He also has a large network of friends related to his church that offer continuing support and counselling to him and his family.

### ***Negotiating the care pathway***

Patients describe some difficulties with their care pathway. This was associated with visiting different hospitals for investigations and treatment and liaison across the different hospital sites.

*I had a session at [Cancer Centre]. There is no liaison. I finished me radiotherapy but then I was left in limbo...There doesn't seem to be a link with the patient... I mean I got home and I thought well what happens now you know( Mr H)..*

Mr H felt unsure about what would happen following his radiotherapy at the cancer centre. He found it unsettling as he didn't know what was going to happen next. Mr D also felt that the different hospitals 'didn't seem to know anything about you', as though the records had not caught up: 'The staff are very good but it's the administration, very slow'. He felt that the problem was with administration and Mr C felt he got lost in the system:

*we seem to lose or get lost in the system because we were diagnosed with the cancer and told we would be seen in a week to start some pre-treatment and then a week after that we'd start the chemotherapy. Well we heard nothing, and we phoned and, well we first of all phoned the nurse ( ) because we're trying to arrange a trip to Holland. And she said, oh no, go on Monday, you will be fine. And, by the Thursday we hadn't heard anything so we phoned and they said, the receptionist said, well could you come in Monday, I said, well I have arranged to go to Holland but if that's a problem but I'll need to know today, I can start trying to change things. I'll come back to you, 'cos she said, we have practices on a Wednesday and a Friday as well, and then nothing happened, we kept on phoning and getting no reply, no-one was phoning back. In the end, we went to Holland, came back on the Tuesday and phoned again and started this process, and they then started offering me a date a couple of weeks hence, I said, she said, we are very full, I said, well I can understand that, I said, but you might be knocking two months off my life.*

Similarly in the Clayson (2007) study problems are reported when patients are under the care of several hospitals so that some of the patients were bewildered by the number of doctors involved in their care and could not determine who was in overall charge. The management of appointments was also identified as difficult.

## Treatment options

Patients did have concerns and felt uncertainties about having chemotherapy treatment. Mrs A for example described how she was talked through her options for treatment:

*I was actually diagnosed on 9<sup>th</sup> May they told me that it was this and ahm but I she talked through the options surgery, chemotherapy, radiotherapy and palliative care and they said they thought that the chemotherapy was the best option.*

However Mrs A decided to discontinue chemotherapy following her first cycle due to problems with side effects. She felt that the treatment was compromising her quality of life. Also Mrs A had been searching for information on the internet:

*I've just been on the internet site for meso and ahm in the booklet that I had they gave me on it it said there wasn't much point in having chemotherapy you know it ahm. So when I was so ill after that first session I was really ill I just couldn't face going having it all done again.*

Mrs A has received information in the booklet she was given that chemotherapy isn't that effective and this is one of the reasons she gives for discontinuing chemotherapy following experiencing side-effects. Apart from Mrs A, who now has a referral for palliative care, Mr J, Mr C, Mr I and Mr J were currently receiving chemotherapy. Mr F and Mr H were waiting to start their chemotherapy treatment.

Mr F felt concerned about having chemotherapy and the stories he had heard about it:

*it's just the, you know you hear so many stories about chemo don't you, I mean, I've never really spoke, I'll be honest with you, I've never really spoken to anybody that's ever had it, so I don't really know it's just the stories that you hear, you know.*

Mr I, although now receiving chemotherapy felt uncertain initially and had thought about refusing it:

*Mr I: Well that was a peculiar...we had counselling to go for chemo which I wasn't going to do.*

*Int: So it sounds like you were against chemo?*

*Mr I: Yeah.*

*Int: Initially...*

*Mr I: Very much.*

*Int: Was that because you'd heard people who'd had it or..?*

*Mr I: In the main yeah, and I mean the condition is terminal, I mean they probably can't do anything with it so what was the point in going through all that. But we were counselled by someone who loves us to go for chemo.*

Mr I understands that his condition is ‘terminal’ and he didn’t see the point in having chemotherapy. Eventually someone in his church whom he trusts counselled him to have it. Also an herbalist he consulted also supported him in accepting chemotherapy. Clayson (2007) also reports how patients have concerns related to having chemotherapy treatment in particular the perceived effectiveness of treatment was an issue.

Mr B, Mr D, Mr E and Mrs G were not offered chemotherapy. Mr D says:

*Int: Did they offer you the chemotherapy?*

*Mr D No they didn’t offer it, but..*

*Mrs D: I think the idea was that you didn’t need it more than anything else, they seemed to think you didn’t need it.*

*Mr D: If it’s like I’m assuming it is, it’s fairly widespread, there’s no point in it, you know.*

*Mrs D Well you don’t know that.*

Mr D is assuming that he wasn’t offered chemotherapy because he has got widespread disease. His wife shows some concern for her husband that he is thinking this is because his disease is widespread. Mr and Mrs D do not seem sure why they haven’t been offered chemotherapy.

## **Contact with asbestos: Legal and Financial Issues**

All the male participants can identify the time when they came into contact with asbestos in their working life. This was often at the start of their working life for example when starting as an apprentice engineer (Mr I). Mr H describes how when he hears about asbestos in the news he began to think back to his own experience having worked with it and ‘*I thought oh bloody hell, is this waiting to pop its head up*’. Mr H is very aware of the link between his previous work and contracting mesothelioma. He is also very precise about the year he came in contact with asbestos on a major building site in central London:

*In 1962 it happened. Working on a big contract that was using a lot of asbestos, there was no protective clothing or anything. That was before, well they must have knew about it but I don’t think they realised how bad it was you know what I mean.*

Mr H describes the lack of protective clothing even when employers were probably aware of the health risks but as he says they didn’t realise how bad it was for the

workers. He therefore lets the employer off the hook by offering an excuse for them. Mr H goes on to describe the chain of exposure not only to himself and hundreds of co-workers but ‘*passers by*’ who ‘*wont have a clue*’ they were exposed to it.

Mr J describes concerns for his wife who washed his clothes when he was working for a heating company:

*Hoping it is not going to contaminate my wife she washed my clothes when I was working for the heating company and I had asbestos all over them.*

Mr J uses the word ‘contaminate’ in this sense his wife is also in danger and potentially ‘contaminated’ due to transferring of asbestos on his clothes to his home. This was a serious concern for Mr J that he could have contaminated his wife. In the interview Mr J came across as very anxious and angry.

Participants also are working closely with solicitors who visit them at home. For example Mr J is awaiting the outcome of investigations in relation to his two previous employers:

*The only thing I’m waiting for is the solicitor following those two companies, which are no longer trading. I have to wait and see and not sure of the outcome.*

Mr H had to go to see a specialist about his Industrial Injury claim:

*Had to go to Portsmouth to see another specialist because it is an Industrial Injury Claim. They want their doctor to do a test, you know.*

Many of the patients received excellent support from the Hampshire Asbestos Support & Awareness Group (HASAG). Mr J describes the great help he has had ‘*I ‘ve had help from HASAG, wonderful people*’.

Mr and Mrs D also identify the help they have had in relation to claiming benefits from HASAG:

*Mrs D: She filled in the forms for the disability.  
Mr D: I haven’t had to do anything’.*

Unlike the men in the study the two women in the study were not aware of having any direct contact with asbestos. All the participants felt well informed about the legal aspects related to this condition. They had good support from hospital services, solicitors and HASAG, which enabled them to complete documentation and



understand what they were entitled to in terms of financial benefits and claims. Mr C describes the process he has been through:

*We were given a list at the hospital of people who might be able to help, and we've chosen one of those that specialises in asbestosis, and I started off by saying that, if this was going to be a lot of work, and all I was going to get out of it was £5,000, I'd prefer to use my time for other uses. I was told it would not involve a lot of my time and in fact he comes to the house and did the, took the witness statement, he typed that all up, sent it through, ask me to read, a couple of amendments, now it's gone back again, well it's on there waiting to be posted. And now I've just been asked to do a financial statement and pensions and things like that. From the first interview he says he believes he's got a case that he's willing to take on which is at no cost to me. So, typically that's six to nine months, rarely go to court, but could do, and other than some correspondence like this.*

All participants felt happy with the advice they had been given in relation to making claims and benefits. They felt very well supported by legal representatives and by HASAG. One participant Mrs A describes not wanting to hear about the compensation claims:

*At first I thought I can't be bothered to go through all of that. I didn't feel as though I wanted to go through that but then ahm ahm my husband said later, 'but you know you might as well you're entitled to it'.*

She felt that claiming was the last thing on her mind following the shock of her diagnosis:

*Mrs A: But that was the last thing on my mind. I can't be bothered to go through claiming you know it was such a shock ahm*

*Int: Of course*

*Mrs A: So ahm I don't think that was such a good idea to say it so early on in a way*

*Int: It might be better for that to come later*

*Mrs A: Just to leave it a bit so you get over your diagnosis and get settled down a bit and then may be say you can apply for compensation.*

*Int: Because everything is so overwhelming*

*Mrs A: It is yes it is such a shock really yeah*

This point brought up by Mrs A is echoed in Clayson's (2007) work as she identifies how the best time to introduce information about financial claims is not clear and raising the issue at diagnosis can be a distraction from the emotionally charged news of an incurable disease. This seems to be the situation for Mrs A as she describes her emotional reaction of feeling overwhelmed and shocked.

# Discussion

The participants in this study describe the effect of a diagnosis of MPM on their emotional well-being. They struggle to come to terms with their diagnosis and experience the shattering of their hopes and dreams for the future. The unpredictability and lack of control described by participants means they feel worried and anxious about what is going to happen to them in the near future and about what to expect. In Clayson's (2007) study she makes the connection between the shock experienced by people at the diagnostic phase, the unpredictability of the future life and a lack of accessible information, which creates fear and a reluctance to ask for help. In this study participant's experience similar shock and unpredictability but they do not describe a lack of accessible information. However they do report how they wish to avoid further 'bad news' and some participants describe a strategy of avoidance of not looking for more information and are generally satisfied with the information they have been given. It is reported in some studies that health care professionals may have negative feelings in relation to the hopelessness of the situation for patients with MPM (Clayson 2007). The feeling of hopelessness may be compounded by the lack of effective treatments and difficulties managing symptoms and can be communicated indirectly to patients (Sweeney et al 2009). One patient clearly demonstrated the importance of non verbal communication skills and in particular eye contact when he was given his diagnosis and prognosis, it almost felt like he was trying to protect the Doctor from having to give such awful news to him. Those entrusted with communicating significant news should not underestimate the skills of the individuals receiving the information. In the present study patients have a rapid physical and emotional transition between experiencing symptoms and receiving a diagnosis of MPM, which they understand to be a terminal illness, which generates a huge amount of anxiety and worry about the future as well as avoidance to enable people to cope day to day.

## ***What are the main symptoms experienced by patients and what strategies do they use to manage symptoms?***

Patient's experience many symptoms, on average they experience six physical symptoms as well as considerable psychosocial distress in the first three months following a diagnosis of PM. The high symptom burden and psychosocial distress is

identified in other studies (Hollen et al 2004, Moore et al 2009). Participants are mainly affected by shortness of breath on exertion, which limits their functional ability and reduces their quality of life. Many patients give up their hobbies and interests such as playing golf, bowls, riding a bike and going for long walks. Coupled with their breathlessness is the feeling of fatigue and tiredness which further restricts their physical capacity. Some patients cope well with physical restrictions and others struggle to adapt their lifestyle and pace their activities. Although one participant had been referred to a breathlessness management course many of the participants manage their breathlessness and tiredness by using common sense strategies such as monitoring themselves after activity, avoiding lifting heavy weights and reducing the amount of walking they do. Participants did find it difficult to pace their activities and they used changes in their physical abilities such as the extent they can walk without becoming breathless to come to conclusions about their disease. Some participants try to push themselves in relation to physical activities and this leads to extreme tiredness and fatigue and can compound emotional distress. One participant felt confident enough to return to work part-time. Conversely another participant felt very unsure about whether or not to return to work even though she was feeling better and missed the social camaraderie at work.

Many patients report loss of weight and loss of appetite. Appetite loss is also reported by 87% (n=495) in a multicentre study of patients with mesothelioma (Hollen et al 2004). Weight loss and anorexia was a considerable problem for one person who lived on his own and he had to force himself to eat. He visibly looked thin and gaunt. He was also waiting to start chemotherapy treatment. Participants need further help and support with nutrition in order to help them maintain their weight, particular support and nutritional counselling is needed for those living on their own.

One problem that was experienced by half of the participants was that of day/night sweats, which caused a lot of distress. It is pointed out by Clayson (2007) that this symptom is not included in the EORTC QLQ-C30, which is one of the validated tools for studying mesothelioma. Therefore the frequency of this symptom is probably underestimated in many studies. There is an urgent need for more research to find ways to successfully palliate this symptom and this would help to improve participants QOL.

Although many patients experienced some pain this was generally well managed by analgesic drugs such as regular Paracetamol or Tramadol. Most patients described mild tenderness, or aches in the chest and side. None of the patients suffered from severe and intense pain at this early stage of the disease.

***To what extent are patients quality of life affected during the first three months following diagnosis?***

Patients QOL is intimately related to their experience of symptoms which is discussed earlier. Participants try to maintain their quality of life by adapting their lifestyle to cope with breathlessness within their daily lives. To a large extent they succeed in adapting to the physical constraints in their lives. As part of the process of adapting they give up many interesting and valuable physical and social activities. The process of adapting enables them to cope with the restrictions that this disease brings.

However, patients have many worries about the future and the terminal nature of their disease. Therefore they suffer psychosocial and emotional distress in relation to the future. One participant was very distressed about the possibility of his wife developing the disease following her contact with asbestos on his clothes and this increased his feeling of anxiety and worry regarding the implications for his wife. The worry and anxiety participant's experience about the future can be incapacitating as they find it hard to comprehend the enormity of the disease and its consequences at this early stage following diagnosis. It can lead to social isolation as people feel embarrassed by weight loss, sweating and other physical changes. An early palliative care referral does offer benefits in that participants can access some form of rehabilitation in terms of breathlessness support as well as psychosocial support.

In the first three months of this disease participants are still coming to terms with what this condition means for them and their loved ones. It is very difficult for people to have some hope and optimism in the early stages of the disease when everything they read and hear about the disease is so negative. A medical professional who developed MPM reflecting on his experience of being diagnosed, describes how staff sometimes acted insensitively by avoiding addressing his emotional issues and his worries and concerns and how this led him to feel devoid of hope despite the fact that his medical care was exemplary (Sweeney et al 2009). Good psychosocial support for patients and their families is essential to maintaining a good QOL.

Patients who were visited at home by a specialist nurse found this very supportive for

example Mrs A. Mr C also felt that he would have like a visit in his home from a specialist nurse. Perhaps this is one feature of the care pathway which could be adapted to enable a personalised visit following diagnosis so patients can talk further with a specialist nurse in their own environment.

Proactive information and support on pacing activity, self management of breathlessness and fatigue would help to improve QOL. These interventions are very well supported by research evidence related to lung cancer at the present time and their adaptation for patients with mesothelioma makes sense.

Further investigation and effective treatments for day/night sweats would help to improve participants QOL. In particular this symptom was embarrassing, interrupted social activities and severely affected and disturbed sleep and there was no effective treatment available for this problem. There is evidence from this study that this is a relatively common symptom that is under investigated.

A number of patients were waiting to start treatment with chemotherapy, and Mr F felt worried about receiving chemotherapy. Mr I was also very unsure about accepting chemotherapy. One patient had discontinued chemotherapy due to a reduction in her quality of life following the experience of side effects. In the Lee et al (2008) study it is also reported that patients discontinued chemotherapy treatments because of debilitating side effects. One participant did not seem sure why he was not receiving chemotherapy and assumed that it was because his disease was advanced. The dilemma that patients faced in relation to chemotherapy treatment was linked with the 'bad news' around MPM as the information they access suggests the limited efficacy of treatment with chemotherapy. Therefore decisions about accepting treatment with chemotherapy did create a dilemma, and the lay network of friends sometimes helped with decision making. The use of CAM is not widespread but it is also reported being used by patients in the Lee et al (2008) study and was found to be beneficial and enhanced coping.

### ***How do patients experience their care pathway?***

Generally participants were seen within the two week rule having presented to their GP with breathlessness and chest pain. One patient in particular Mrs A had a very prolonged period before she was diagnosed due to a co-morbidity- a cardiac problem.

This was very distressing for Mrs A and she had to change her GP in order to be referred for her breathlessness and pain to a hospital consultant.

At times the participants had difficulty understanding who was in charge of their care when they moved across hospitals for investigations and treatment. They did not have any insight into the multidisciplinary nature of the caring team and some participants report seeing different doctors in clinic so they felt they lacked continuity. They were at times unsure about what the next step in the treatment trajectory was and they report some problems with administrative delays across treatment centres.

There is a need to consider the best time to introduce information about financial claims. Clayson (2007) recommends that in most cases it is best to avoid introducing information about financial claims at diagnosis, because it may distract from the emotional and psychosocial reactions to the disease. Mrs A felt strongly that information about financial claims should be introduced later not at the diagnostic consultation. Sweeney et al (2009) identify some gaps in psychosocial care at diagnosis with an overemphasis on information giving and a lack of attention to emotional issues.

### ***How and when do patients access palliative care services and other agencies?***

Three patients had received a palliative care referral Mrs A, Mr B and Mrs G. Mrs A had a home visit from the community palliative care nurse that she found very helpful. In the Lee et al (2008) study it was found that patients and carers report positive benefits to being referred to palliative care services despite initially feeling shocked because they linked palliative care to 'the end was near'. Receiving a palliative care referral also meant that patients and carers had to face up to the terminal nature of the disease. Mr B was in the process of being referred to palliative care as was Mrs G. Very few participants were accessing any additional services as most of them felt they wanted to remain independent at this stage. They did not feel they needed any extra help and saw this need as a slippery slope to dependence.

In the present study, as well as in others, it was found that patients can be undemanding of services and many reasons have been found for this such as only seeking support within the family and feeling reluctant to access outside support (Lee et al 2008), and stoic acceptance (Clayson et al 2005). There is evidence therefore

that waiting for patients to ask for services will not work. Clayson (2007) recommends a proactive approach to caring for this group of patients. However a supportive rehabilitative approach may be applicable combining physical and psychosocial interventions to support and enhance a good quality of life early in the disease trajectory. A number of participants had received a home visit from representatives of HASAG and on this visit they were given advice and help in relation to finances including claiming benefits and filling in claim forms, which they all found very helpful.

### ***Limitations of the study***

This study is limited by a small sample size and participants were living in an affluent part of the UK. Therefore the findings of this study may not be generalisable to the experience of patients in other parts of the UK. The study only reports on the patient's experience during the first three months of the disease trajectory; therefore symptom experiences and quality of life issues only reflect this early stage of the disease. The study is also limited by the fact that a couple of people were not able to be interviewed for example feeling too unwell.

# Recommendations following the study

1. Proactive management and early identification of breathlessness as a symptom would not only be beneficial to the patient but better serve the health economy as it remains one of the top three reasons along with pain and infection for patient admissions to the Acute Trust. A local breathlessness management course would enhance the patient's ability to cope with this debilitating symptom. Local courses for health care professionals to ensure they are able to provide optimum support to patients is also recommended.
2. Patients should be offered information and advice on Pacing at diagnosis either by using the national patient information system or if not available by developing information locally. Patients are restricting their activities but have not been given specific advice as to the best way to pace their activities. Together with this there is a need to include information on the local multi disciplinary team and locality of treatments in order to provide clarity on the care pathway. A network wide approach could be adopted to develop this information.
3. There is a need to ensure that the role of the Key Worker (in this instance the specialist nurses) is embedded into local practice. The specialist nurse also needs to be supported by other named specialists in the case of absence, as patients and carers found this role to be beneficial and supportive. Innovative and more flexible ways of providing care could be considered, such as specialist nurses/key worker working across both the community and the acute Trusts caring for the patient in their preferred place of care and following the patient into hospital should this be required. Honorary contracts in the Cancer Centres for those nurses working in the Acute Trusts would also be helpful enabling the Nurse to follow the patient through their treatment. Developing a greater understanding of the difficulties faced in the various care settings for the patient and the carer would help to improve the patient experience and quality of care provided.
4. Those that were referred for specialist palliative care found this helpful to discuss his/her uncertainty about the future and symptom management. Not all patients reported difficult symptoms, indeed some patients felt remarkably well. Clinical Nurse Specialists (CNS) were able to offer supportive care and the study demonstrates that



patients did feel supported but at the risk of leaving the need for specialist palliative care unmet.

5. It is recommended that early referral to the community palliative care team is considered and that there is close liaison between specialist palliative care and the CNS in order to optimize total support for the patient. There remains local and possibly national work to be considered around managing patients expectations on referral to specialist palliative care teams.
6. This study supports the National Advanced Communication Skills course as being mandatory for specialist nurses and doctors. Patients feel very well supported if communication of significant news such as news of a very poor prognosis is delivered in an empathetic and skilful manner.
7. Clarity is needed around the rationale for treatment decisions, particularly around chemotherapy; although rationales for treatment are clearly stated in the Backup booklet 'Understanding Mesothelioma', which is given to patients at diagnosis. Oncologists may need to prioritise information about treatment as it appears that a lack of understanding by the patient, coupled with the negativity around the disease and prognosis, makes it hard for patients to accept chemotherapy and to continue with chemotherapy when side effects are experienced. The research team awaits the results of the National CHIMP audit which may further inform the clinical picture.
8. Referral to a Dietician is necessary at diagnosis as well as on-going nutritional counselling as the majority of patients suffered weight loss and anorexia.
9. Further investigation is needed to find effective ways of managing day/night sweats as 50% of patients found this to be a distressing symptom. Although there is evidence to support interventions in patients with sweating due to hormone deficiency there is a paucity of evidence to support treatments in paraneoplastic sweating. It is recommended that this symptom is included in patient assessments and that some practical advice is offered to patients.
10. Many patients benefited from referral to HASAG and found the support and home visit very helpful. Therefore all patients should be made aware of their local asbestos support group.

11. Finally consideration should be given to setting up a local support group for patients with Mesothelioma and Lung cancer to provide social support and to include professionals, patients, carers and network partnership support.

# References

- British Lung Foundation (2009) Survey of mesothelioma patients and their carers. BLF, London.
- British thoracic Society Standards of Care Committee (2001) *Thorax*, 56:250-265.
- Cancer Research UK 2009 Cancer Statistics Incidence  
[http://info.cancerresearchuk.org/prod\\_consump/groups/cr\\_common/@nre/@sta/documents/generalcontent/crukmig\\_1000ast-2735.pdf](http://info.cancerresearchuk.org/prod_consump/groups/cr_common/@nre/@sta/documents/generalcontent/crukmig_1000ast-2735.pdf) Accessed 1st March 2010
- Chapple A, Ziebland S, McPherson A (2004) Stigma, shame and blame experienced by patients with lung cancer; a qualitative study. *British Medical Journal* 328,7454:1470-1475.
- Clayson H (2007) The Experience of Mesothelioma in Northern England. Unpublished MD thesis. Academic Unit of Supportive Care, University of Sheffield, UK.
- Corner J, Hopkinson J, Roffe L (2006) Experience of health changes and reasons for delay in seeking care: a UK study of the months prior to the diagnosis of lung cancer. *Social Science & Medicine*, 62:1381-1391.
- Department of Health (2007) The Mesothelioma Framework. London, Department of Health Gateway reference 7907.
- Glaser B and Strauss A (1967) The discovery of grounded theory Chicago, Aldine.
- Hawley R, Monk A, Wiltshire J (2004) The Mesothelioma Journey: Developing strategies to meet the needs of people with mesothelioma their family carers and health professionals involved in their care. The University of Sydney, Sydney, Australia.
- Hollen PJ, Gralla RJ, Liepa AM, Symanowski JT, Rusthoven JJ (2004) Adapting the lung cancer symptom scale (LCSS) to mesothelioma. *Cancer* 101:587-595.
- Hughes N, Arber A (2008) The lived experience of patients with pleural mesothelioma. *International Journal of Palliative Nursing* 14,2:66-71.
- Hughes N (2006) The first time I told my story. A phenomenological study of the lived experience of mesothelioma. Unpublished Msc dissertation, University of Surrey.
- Krishnasamy M, Wilkie E, Haviland J (2001) Lung cancer health care needs assessment: patients' and informal carers' responses to a national mail questionnaire survey. *Palliative Medicine*, 15:213-227.
- Lee S, O'Connor M, Chapman Y, Humphreys J, Hamilton V, Cass B (2008) A Very Public Death. Dying of mesothelioma and asbestos-related lung cancer in the Latrobe Valley. Faculty of Medicine, Nursing and Health Sciences, Monash University, Frankston, Victoria 3199, Australia.
- Li J and Gigris A (2006) Supportive care needs; Are patients with lung cancer a neglected population? *Psycho-Oncology*. 15 509-516.
- Moore S, Darlison L, Todd AM (2009) Living with mesothelioma. A literature review. *European Journal of Cancer Care* (In Press).

Peto J, Hodgson JT, Matthews FE, Jones JR (1995) Continuing increase in mesothelioma mortality in Britain *The Lancet*, 345: 535-539.

Sweeney K Toy L, Cornwell J (2009) A Patient's Journey Mesothelioma. *BMJ*, 339, 511-514.

Yates DH, Corrin B, Stidolph PN, Browne K (1997) Malignant mesothelioma in south east England: clinicopathological experience of 272 cases. *Thorax*, 52:507-512.

# Appendix 1

## Topic Guide for Patient Interviews

### *Function/Quality of Life and Decline*

When did you start feeling ill?

What made you feel you needed to go to your doctor?

How long did it take for you to receive a diagnosis?

What were you able to do when you first went to a doctor?

What are you able to do now?

How far could you walk when you first went to your doctor?

How far can you walk now?

Are you still working?

Probe: type of work engaged in now and in the past

Probe: If not when and why did you stop working?

### *Symptoms and strategies*

How are you feeling at the moment?

What symptoms are you experiencing?

Probe: breathlessness, pain, anorexia

How do your symptoms affect your daily life?

Is there anything else you would like to add about your symptoms or the way you are feeling?

What strategies do you use to help you cope on a daily basis?

Is there anything else you can think of that may be helpful to you or your carers?

### *Information and Support*

What kind of information were you given at diagnosis to help you and your family to understand your illness?

Probe: Have you been able to access information other than from health services?

Who could you contact if you require further support or information?

How do you feel about the information and support you have received?

Who is supporting you and your family at the moment?

Probe: GP, DN, Nurse Specialist, Specialist medical consultant, Palliative care or other.

### *Referral to Palliative care*

Were you offered referral to a palliative care team?  
Did you accept this referral?  
Probe: if you said no why was this.

If you weren't offered palliative care input would you have liked to have been?

To whom were you referred?  
Probe: hospital/ community palliative care teams.

When you were offered palliative care input was this at the right time for you?  
Probe: level of contact with palliative care and contact with GP services

How have you found support from palliative care services?

Probe: access to other services e.g. occupational therapy, physiotherapy, social work, counselling, social care

What other support do you think you need?

## Appendix 2

**Table 1 Demographic Information and type of mesothelioma**

Patient	Symptoms started	Diagnosis	Type	Occupation	Baseline Performance Status	Deceased	Age
Mrs A	March 07	9/5/08	Epithelioid	Part time library work	PS0		61
Mr B	April/May 08	23/05/08	Epithelioid	Retired land surveyor	PS2	04/11/08	80
Mr C	Feb 07	26/09/08	Epithelioid	Consultant electrical engineer	PS1		64
Mr D	July 08	Aug 08	Epithelioid	Retired metal work	PS1	10/06/09	72
Mr E	June 08	Aug 08	Epithelioid	Retired Plumber	PS1	30/11/09	74
Mr F	Oct 08	28/11/08	Spindle cell	Retired coach builder	PS1	13/05/09	72
Mrs G	Feb 09	3/4/09	Sarcomatoid	Housewife	PS2	5/9/09	82
Mr H	March 09	May 09	Unknown	Retired builder	PS1		74
Mr I	March 09	30/4/09	Epithelioid	Electrician/ Runs own business now	PS1		56
Mr J	Feb 09	5/6/09	Epithelioid	Retired Heating engineer	PS1		68

# Appendix 3

**Table 2 Symptoms experienced**

	Cough	Breathlessness	Weight loss	Fatigue/tiredness	Pain	Pleural effusion	Anorexia	Problem sleeping	Heartburn/Indigestion	Night/day sweats
Mrs A		√		√	√ around ribs, ache, tenderness	√			√	
B		√		√	No	√				√
C		√	√	√	√ chest pain when lifting	√	√	√		√
D		√	√	√	√ tightness like nerve ending pain	√				√
E	√	√		√	No	√	√			√
F	√	√	√	√	No		√		√	
Mrs G		√	√	√	√ at night, sore and tender	√	√			
H	√	√	√	√	√ sore	√	√	√		√
I	√	√	√	√	No	√		√		
J		√	√		√ ache in chest	√	√		√	