MESOTHELIOMA UK

The University Of Sheffield.

The Gendered Experience of Mesothelioma Study (GEMS)

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Abstract

Background

This mixed method study explored men's and women's experiences of living with mesothelioma. The aim of the Gendered Experience of Mesothelioma Study was to generate insights into the experience and health/support needs of men and women living with mesothelioma. Specifically, similarities and differences in experiences between men and women participants along these journeys were examined. These insights were then used to identify how health, legal and social professionals and support agencies might best support men and women living with mesothelioma.

Methods

Quantitative data was derived from two data sources: HASAG, an asbestos support group based in Hampshire, and the Mesothelioma UK-funded Mesothelioma Outcomes, Research and Experience (MORE) survey.

Semi-structured interviews were conducted with 11 women and 13 men living with mesothelioma (n=24). Interviews were carried out between July and December 2019. Interviews ranged in duration from 31 to 113 minutes and were digitally recorded and transcribed verbatim. Analysis of the data was carried out using thematic analysis (Braun & Clarke, 2006).

Findings

Eight key findings have been generated from the research and are presented here. These are as follows:

1. High risk occupations for men differed from high risk occupations for women
2. Women of all ages and younger men lacked awareness of the dangers of asbestos exposure
3. Gender differences existed in the experiences of explanations and support provided at the time of diagnosis
4. Men and women's roles within the family and society influenced how they coped with a diagnosis of mesothelioma
5. No significant gender differences were reported in treatment and care experiences following diagnosis
6. Men and women had different ways of communicating with professionals along the mesothelioma pathway
7. Preferences for the types of support desired showed some differences between men and women
8. Familial and social expectations of men and women influenced their willingness to pursue civil compensation

Implications for practice have been identified. These focus on the medical, financial, legal and support needs and preferences that men and women may have.

Conclusions

GEMS provides valuable insights into the experiences of women and men living with mesothelioma. The findings and implications from GEMS will provide some guidance and support for professionals working with men and women living with mesothelioma.

Executive summary

The purpose of this report is to summarise the key findings and implications for practice of the Gendered Experience of Mesothelioma Study (GEMS). GEMS uses data provided by Mesothelioma Outcomes, Research and Experience (MORE) survey, HASAG, and individual and group interviews.

The data has been collated to develop key findings and implications for practice.

The report presents eight key findings around the gendered experiences of mesothelioma. Each key finding has implications for practice to support health and other practitioners working with men and women living with mesothelioma.

Several implications for practice have been presented. There were three key areas in which implications for practice were developed. These focused on improving awareness of the dangers of asbestos, offering support and information which considers gender differences, and exploring the barriers to seeking and receiving benefits/compensation for women and men.

GEMS was funded through Mesothelioma UK. It is supported by an advisory group of stakeholders including Mesothelioma UK health professionals, solicitors, asbestos support group workers, barristers and lay representatives.

The research is being conducted by the Mesothelioma Patient Experience Research Group at the School of Nursing and Midwifery, University of Sheffield. The team has expertise in research into mesothelioma experience and gender studies.

Key findings are reported as follows:
Key finding 1 - High risk occupations for men differed from high risk occupations for women

Key finding 2 - Women of all ages and younger men lacked awareness of the dangers of asbestos exposure

Key finding 3 - Gender differences existed in the experiences of explanations and support provided at the time of diagnosis

Key findings 4 - Men and women's roles within the family and society influenced how they coped with a diagnosis of mesothelioma

Key finding 5 - No significant gender differences were reported in treatment and care experiences following diagnosis

Key finding 6 - Men and women had different ways of communicating with professionals along the mesothelioma pathway

Key finding 7 - Preferences for the types of support desired showed some differences between men and women

Key finding 8 - Familial and social expectations of men and women influenced their willingness to pursue civil compensation

The Gendered Experience of Mesothelioma Study (GEMS)

1. Introduction

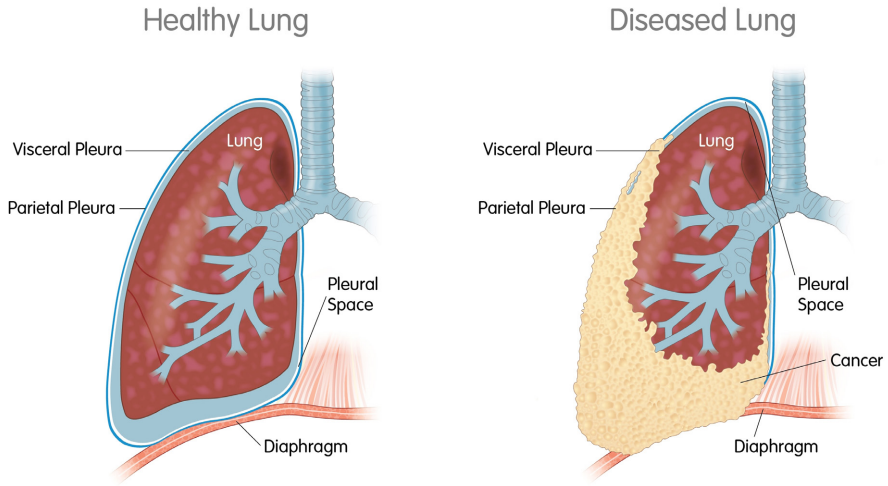
This report presents an overview of the Gendered Experience of Mesothelioma Study (GEMS). A background section provides a summary of the context within which the study was conducted. This is followed by a brief description of the quantitative and qualitative methods. Eight key findings are then discussed along with their implications for practice.

GEMS was conducted by a research team at the University of Sheffield, Division of Nursing and Midwifery. It was funded through Mesothelioma UK.

2. Background

Mesothelioma
Mesothelioma is an aggressive, rare cancer resulting from exposure to and inhalation of asbestos (Health and Executive, 2019; Odgerel et al 2017). Incidence is higher in certain occupational groups including asbestos mining and the disposal and construction industries (Rake et al 2009). These are industries and occupations that have traditionally had higher rates of male employment. The incidence rates of mesothelioma vary within and across countries. The UK has approximately 2,700 new diagnoses per year, one of the highest internationally (Cancer Research UK (CRUK) 2020; Royal College of Physicians 2020). The incidence rates of mesothelioma show no signs of reducing. Global incidence and burden are likely to be under-reported due to poor data capture in some countries. Whilst asbestos use has drastically reduced in developed countries, significant amounts of asbestos are still used in India, China, Russia and some developing countries (Frank & Joshi 2016).

Mesothelioma is predominantly a pleural disease (89% in the UK), however, it can occur less commonly in the peritoneum (3% in the UK) or testes and other unspecified sites (8% in the UK) (CRUK 2020). However, it is noteworthy that peritoneal mesothelioma is challenging to diagnose. Some sources report that peritoneal mesothelioma may account for up to 30% of mesothelioma diagnoses (Kim et al. 2017).



Mesothelioma is more common in men with 83% of cases occurring in men and 17% in women. In 2017, this equated to 2,223 men and 256 women being diagnosed with mesothelioma (CRUK 2020). The latency period for mesothelioma varies from 30 to 50 years with an average of 40. Occasionally, exposure to diagnosis can be 10 years or less, but this is uncommon.

Mesothelioma is an incurable cancer. Almost 60% of people diagnosed with mesothelioma will die within a year of learning that they have the disease (Royal College of Physicians 2020). However, there is a growing number of treatments and trials. In the past 12 years, new radical surgical procedures are being performed, novel drug treatments have been developed and radiotherapy techniques are evolving. These all seek to provide better patient outcomes (Bibby & Maskell 2018). In addition, there are new procedures for better management of the consequences of malignant pleural mesothelioma such as trapped lung and malignant pleural effusion (MPE). New drugs, surgical procedures and radiotherapy techniques offer promise in terms of length and quality of life. As these treatment interventions start to be rolled out into practice, it is important that all those who are eligible have access to them. It is therefore necessary to explore any factors influencing access to and uptake of new treatments to avoid potential inequalities, including those based on gender.

Sex, gender and mesothelioma
Sex differences in cancer epidemiology are widely accepted. Men are more prone to die from cancer and this sex difference is often attributed to regulation at the genetic/molecular level and sex hormones such as oestrogen (Kim et al, 2018). In lung cancer, it has been

noted that, while women are more susceptible to tobacco smoke (Kiyohara & Ohno, 2010), they are usually diagnosed with less advanced disease (Sagerup et al, 2011) and have a better prognosis and survival (Kinoshita et al, 2017).

Specifically, in regards to mesothelioma, little research on sex and gender differences has been undertaken other than that relating to incidence and prevalence. Previous studies also show differences between men and women in treatment rates and survival rates (Taioli et al, 2014). However, there is evidence to suggest that some aspects of the experience of living with mesothelioma may differ between men and women.

For example, a recent study identified that women diagnosed with mesothelioma may be less likely to receive surgery or chemotherapy (Barsky et al. 2020). The factors contributing to this disparity remain unknown and further exploration into the experiences of treatment and care along the mesothelioma pathway is required. Despite a potential disparity in treatment received, women have been shown to have far higher survival rates even when age, stage and race were accounted for (Taioli et al, 2014). This latter study suggests that differences in asbestos exposure and tumour biology may all play a role in generating these survival statistics. Certainly, mesothelioma has been shown to be more aggressive in men; more invasive to the chest wall, pericardium, mediastinum and diaphragm, and more metastasizing (Rahouma et al, 2017). An additional difference highlighted in the literature is, similar to women's greater susceptibility to smoke exposure and lung cancer, that there is also some evidence that women have a steeper dose-response curve in relation to asbestos exposure and mesothelioma, again suggesting greater susceptibility (Reid et al, 2007).

Evidence also suggests that since the early 1990s, mesothelioma incidence rates in females have doubled (97%), and rates in males have increased by around half (51%) (CRUK 2020). The difference between incidence rates for men and women is an additional motivation for exploring the experiences of living with mesothelioma from a gendered perspective.

Experience of clinical and legal professionals also indicates that women may have a different experience to men regarding mesothelioma in terms of awareness of the disease, risk and exposure, presentation and diagnosis, access to treatment and compensation and legal processes. Asbestos websites such as Asbesotos.com (2020) have suggested that the experiences of women may differ in the areas listed above. Discussion and anecdote have generated concerns that women with mesothelioma may:

- Be less likely to be aware of their exposure and risk
- Be less likely to have a clear occupational link
- Be less likely to be diagnosed quickly and at an early stage
- Encounter assumptions that they have been exposed through para-occupation e.g. from work clothes of male family member rather than their own occupation or environmental exposure.
- Be less likely to have a claim for compensation processed

Limited research has been conducted to explore these assumptions and views.

'The Gendered Experiences of Mesothelioma Study (GEMS) aimed to generate evidence and understanding about the gendered experiences of mesothelioma in order to identify the implications for health, social care and legal practices.'

3. Methods and analysis

GEMS is a mixed method study exploring the understanding and support needs of men and women living with mesothelioma. In this section, the quantitative methods and analysis are initially presented followed by the qualitative methods and analysis. Data sharing agreements and research ethics approvals were in place prior to the study commencing.

3.1 Quantitative methods and analysis

Analysis of data from two sources is presented. These sources are a national dataset of clients receiving services from an Asbestos Support Group (ASG) in the UK and the Mesothelioma Outcomes, Research and Experience (MORE) survey, funded by Mesothelioma UK (Mesothelioma UK 2020). Descriptive statistical analysis was performed using SPSS. The findings are summarised below. Although they do not provide a complete picture, these findings provide important context for the qualitative work that follows.

HASAG database

HASAG is an Asbestos Support Group (ASG) based in Southampton. It provides support and advice to people with mesothelioma and their families. HASAG's client base focuses on the south and south east of England but does take referrals from elsewhere in the UK.

HASAG routinely collects the data of men and women diagnosed with mesothelioma. The data considered here was collected between January 2016 and December 2018. We obtained the anonymised HASAG data for analysis. In total, there were 1,177 mesothelioma cases (971/82.5 per cent were men and 206/17.5 per cent were women). There are more very young women in the dataset (younger than 50yrs). 5 per cent of women (n=10) were under the age of 50 versus 0.5 per cent of men (n=5).

Mesothelioma Outcomes, Research and Experience (MORE) survey

The MORE survey was conducted by Mesothelioma UK in 2019 (Mesothelioma UK 2020). MORE is a UK-based observational prospective cross-sectional survey where data was collected directly from patients on their experience of mesothelioma, their health related quality of life and current clinical management. Recruitment was conducted by Mesothelioma UK via their website, social networking groups/links and specialist nurse network. The participants completed an online survey, the medical sections of which were then validated by a specialist nurse.

Complete responses were received from 503 participants. 97 (19.4 per cent) were women and 403 (80.6 per cent) were men. We obtained the anonymised MORE data for analysis.

3.2 Qualitative methods and analysis

This section provides detail on how the qualitative, interview-based component of GEMS was conducted. This includes how participants were recruited, who took part, and how the data was collected and analysed.

Recruitment

Invitations to participate in GEMS were circulated to patients via Mesothelioma UK and ASGs. Information was distributed by Mesothelioma UK using its newsletters and social media. People were asked to contact the Mesothelioma UK information line if interested in participating. When contacted, the information line staff discussed the study. They then liaised with the research team if people were interested in participating. Additionally, advice workers from ASGs discussed the study with men and women living with mesothelioma and then liaised with the research team if the person was interested in participating. An information sheet and a consent form were then sent via post or email for the person to consider.

Data collection

Interview topic guides were informed by the available literature and findings from previous studies undertaken by the research group. The project advisory group also supported topic guide development. Topics included the participant's occupational history as well as their experiences through the mesothelioma journey (a full topic guide can be viewed in Appendix 1).

Women	Age	Men	Age
F1 Amy	78	M1 Arthur	70
F2 Belinda	81	M2 Ben	62
F3 Cath	79	M3 Callum	62
F4 Donna	31	M4 Derek	66
F5 Edna	68	M5 Eddie	78
F6 Fiona	75	M6 Fred	77
F7 Grace	32	M7 Graham	72
F8 Hannah	65	M8 Ivan	63
F9 Irene	55	M9 Henry	76
F10 Julia	65	M10 Jude	68
F11 Kay	80+	M11 Kevin	52
		M12 Lenny	44
		M13 Mike	74

Table 1: Participant characteristics

Semi-structured interviews were undertaken between July and December 2019. Consent was obtained and verified prior to the interview. Interviews lasted between 31 and 113 minutes and were audio recorded. All interviews were conducted over the telephone. Using telephone interviews enabled people to participate from across the UK. This method also proved more convenient for interviewees and less burdensome.

Sample

The final interview sample consisted of 11 women and 13 men. Three women and two men were living with peritoneal mesothelioma. The remaining participants were living with pleural mesothelioma. At the participants' request, three of the interviews were conducted with a family member present.

Participants' ages ranged from 31 to 89 (women 31-89 years; men 44-77 years). Time since diagnosis ranged from five months to 10 years. Pseudonyms have been used to refer to participants to preserve anonymity.

Data analysis

The anonymised interview transcripts were uploaded into QUIRKOS (a qualitative analysis software package). QUIRKOS was used to manage and search the data. Thematic analysis methods were used to ensure a systematic and rigorous progression through six analytic phases: familiarisation with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing a report (Braun & Clarke 2006).

The data was analysed by the research team. Data coding and categorisation were discussed at regular intervals and consensus reached among research team members. The emerging themes were also challenged and verified in a focus group with mesothelioma nurse specialists, meetings with three key stakeholders (two daughters of women who had died of mesothelioma and one solicitor) and during advisory group meetings.

4. Key findings and implications for practice

This section presents eight key findings. There was important crossover between the quantitative and qualitative data, and these are therefore integrated within this section. Some findings rely more on one source of data than another. Nevertheless, they collectively represent the most important issues emerging from the data in relation to gendered experiences of mesothelioma. All quotations use pseudonyms and are anonymised.

Key finding 1 - High risk occupations for men differed from high risk occupations for women

From the analysis of HASAG data and the interview transcripts, there is an indication that the list of occupations where women were exposed to asbestos differed from that of men. Men were most frequently exposed in construction-related occupations due to direct handling of asbestos. (See Table 2). The findings show that, for women, exposure at work was most frequently linked to the working environment rather than the direct handling of asbestos and the most frequent occupation was that of administration e.g. office work.

The interview data also noted these differences in occupational exposure to asbestos. Four of the women interviewed were secretaries and others worked in administrative roles. Some queried whether their work environment may have been where they were exposed to asbestos:

Occupation	Female	Male	
Builder	6 (3%)	113 (11.6%)	
Carpenter	0	138 (14.2%)	
Electrician	2 (1%)	79 (8%)	
Engineer	2 (1%)	135 (14%)	
Plumber	2 (1%)	65 (7%)	
Admin/Clerical	65 (31.3%)	33 (3.4%)	p=0.04
Factory	11 (5%)	23 (2.4%)	p=0.45
Health	11 (5%)	14 (1%)	p=0.86
Sales	8 (4%)	18 (2%)	p=0.76
Teacher	18 (9%)	8 (0.8%)	p=0.63
Total	125/207 (60.3%)	626/971 (%)	

Table 2: Occupation - P<.05

"It was suggested that my work in schools may have been somewhere [that I was exposed to asbestos]. I did move around different schools." **F3 Cath (secretary)**

"When I first started work, they were building a new office block next door to where I worked and we think that that's probably the most likely source." **F9 Irene (office worker)**

For other women interviewed, para-occupational exposure was commonly considered the most likely source of asbestos exposure. However, some women who initially thought that para-occupational exposure was their only source of exposure later found that they may have been exposed through their own work:

"I was a setter's mate. […] there was asbestos all around the burners. But I didn't know all that, I'd gone into all that myself and realised that's where the asbestos was. I've only just really been looking at it. So, I didn't know really until about two years ago that there had been a case that won. So, there was a case. I only found out through another support group that said to me 'oh yeah, we've had a case.'" **F1 Amy**

This key finding highlights that for women, what constitutes a high-risk occupation may need to be considered differently to that of men. It also suggests that considering exposure from more than one source e.g. para-occupational and occupational, may be beneficial when taking an occupational history.

Implications for practice

- Do not presume asbestos exposure for women is always para-occupational. They may have been exposed to chronic low levels of asbestos through their own working environment. This is particularly the case where the buildings in which they worked (schools, hospitals, offices), were built at the height of asbestos use, and are now beginning to age and decay. This raises the importance of occupational history taking that assesses the working environment as well as occupational role
- Raise awareness of compensation cases that have been won for people who have never worked directly with asbestos. Raising awareness of these cases may encourage more people living with mesothelioma to explore their options around seeking compensation

Key finding 2 - Women of all ages and younger men lacked awareness of the dangers of asbestos exposure

'Our findings highlighted that, prior to diagnosis, women of all ages and younger men lacked awareness of the dangers of asbestos exposure.'

This lack of knowledge and awareness led to confusion, and occasionally denial, at diagnosis. This contrasted with participants who had prior knowledge of asbestos related diseases, some of whom spoke about a sense of inevitability regarding their diagnosis. Both a lack of knowledge and having prior knowledge of asbestos related diseases have implications for practice at the point of diagnosis.

People who have worked extensively with asbestos, or acquired mesothelioma through para-occupational exposure (usually via fathers or husbands), may have knowledge of the dangers of asbestos prior to diagnosis. This awareness will have been developed through attending work-related health and safety courses for those in high risk occupations or because loved ones or colleagues have died from asbestos-related diseases:

"I just knew that [husband] worked with it. So, I just knew that asbestos caused [cancer]… [My husband] worked in the dockyard and he loved all his friends. Gradually one by one they were dying with cancer as we thought, lung cancer." **F1 Amy**

"I mean I was amongst it and in it and if anybody was going to get mesothelioma it was me, and anybody else who worked there actually." **M6 Fred**

This was in stark contrast to many of the women and younger participants, who had not worked or lived with someone who worked in an asbestos-related industry and had never heard of mesothelioma prior to diagnosis:

Para-occupational exposure is defined in this report as "…exposure outside work activities but resulting from the work activities of others, for example, laundering overalls used by asbestos workers" (Darnton & Hutchings, 2012, p. 3)

"I was told I had something called mesothelioma, which I had no idea what it was." **M11 Kevin (aged 52)**

"...I wasn't questioning, I mean, I didn't know what asbestos was…what mesothelioma was...I couldn't believe it, it took along time to sink in." **F2 Belinda (aged 81)**

Those with extensive knowledge of asbestos-related diseases may require support to process their preconceived understanding of what a diagnosis of mesothelioma means. For example, as implied in the above quote from Amy, their experience may go back sometime when fewer trials were available, treatment was less developed and outcomes particularly stark. Conversely, those with no or little prior knowledge of mesothelioma and asbestos-related diseases may need additional information and time to understand their diagnosis and the possible implications of this.

For many of the women and younger men, awareness of the dangers of asbestos and where it could be found came after diagnosis. Their awareness was often raised following discussions with health and legal professionals, as well as through support group members:

"...I didn't really know a great deal about it [asbestos exposure and peritoneal mesothelioma];...then after my surgery I was flung into a survivor group…I think it was only through that, that gradually over the months it occurred to me that asbestos was a possible cause." **F9 Irene**

Interviewer: "Do you know where you might have been exposed?"
M12 Lenny: "No."
Interviewer: "Do you have any suspicions?"
M12 Lenny: "No. I did some gas meter reading while I was at university, so I've been able to claim that benefit by stating that. They [the solicitors] looked into that, but it could never be proven."

"I never really thought about it [where I was exposed to asbestos] at first but I've had a lot of thinking time and I'm pretty sure that [renovations of the school building is where I was exposed to asbestos]…" **F7 Irene**

If people generally are unaware of where asbestos may be found (e.g. in buildings), this may lead to people inadvertently coming into contact with it during their working lives. This suggests the need for increased social awareness of where asbestos can be found, what it looks like and the procedure to follow if it is found. This key finding has implications for mesothelioma prevention as well as types of support required at diagnosis.

Implications for practice

- Patients with prior experience of mesothelioma e.g. through colleagues/family members dying from mesothelioma, may have a greater need for emotional support and current information. There are many more options for mesothelioma treatment, trials, symptom management and support than were available historically. Patients with prior experience of mesothelioma may have connotations of a family member or colleagues experience from many years ago. Reassuring patients that the care and treatment options have improved is important
- Patients without prior knowledge of mesothelioma may need additional information and time to understand their diagnosis of mesothelioma. Without prior knowledge of asbestos-related diseases, it may be challenging to understand and accept a diagnosis of mesothelioma. Ensuring that these patients, who are more often women or younger men, are provided with adequate information and time to ask questions is essential
- Develop resources to increase the awareness of asbestos risk in workplaces. This may include online courses and assessment tools. Encouraging employers to make use of the resource is also important to ensure impact in practice

Key finding 3 - Gender differences existed in the experiences of explanations and support provided at the time of diagnosis

Using the MORE data, key finding three suggests that there were also some differences in women's and men's experiences around the time of diagnosis. Women were less satisfied that explanations of mesothelioma were given in an understandable way, were less likely to think that the doctor knew enough about their condition and less likely to report a good, overall experience of professionals working together to provide the best possible care at the time of diagnosis.

Key findings one and two highlight that women may be less aware of their past asbestos exposure and more likely to have worked in a job where they were not directly-handling asbestos. These factors may contribute to women having less knowledge of asbestos, asbestos-related diseases and the dangers of asbestos. This may mean that at diagnosis, women require additional information (and therefore additional time) from their healthcare professional and perhaps information that is communicated in a different way to men with previous experience with asbestos.

'While there were few statistically significant differences, it is possible that they had a negative cumulative effect on the women's experiences at the point of diagnosis.'

Diagnosis-related Question	Men		Women		p-value
	Yes (%)	No (%)	Yes (%)	No (%)	
Q1.19. Was the explanation of the mesothelioma diagnosis given in an understandable way?	66.6	33.4	49.3	50.7	p=0.07
Q1.20. Was the explanation given in a sensitive way?	73.3	26.7	76.6	29.4	P=0.67
Q1.21. Did someone explain that a multidisciplinary team had reviewed your case (both diagnosis and treatment)?	76.1	23.9	67.3	32.7	Pleural: p=0.3 Peritoneal p= 0.034 (see additional table by Type)
Q1.27. Do you think that the doctors diagnosing mesothelioma knew enough about the condition and treatment?	77.9	22.1	69.6	30.4	Both types (see additional table below by Type, where differences are significant)
Q1.35. Was good support received from your GP in relation to your mesothelioma diagnosis?	45.5	54.5	47	53	p=0.8
Q1.46. Overall have all the professionals involved in your diagnosis worked well together to provide the best possible care?	80.6	19.4	78.3	21.7	Pleural: p=0.68 Peritoneal: p=0.80

Table 3: Explanation and support at time of diagnosis P<.05

Not only do women have additional challenges in terms of diagnostic experience, fewer women have the support of a next of kin to help them at this time. The HASAG data indicated that of the cohort members, fewer women reported having a next of kin (75 per cent) vs men (82.5 per cent). In addition, fewer women reported having a spouse/partner (46 per cent vs men 63 per cent).

Some of these differences, such as whether the diagnosing doctor had sufficient knowledge of their condition, became even more marked when considering the specific type of mesothelioma. 60 per cent of women (compared to 33 per cent of men) with peritoneal mesothelioma believed that their diagnosing doctor lacked sufficient knowledge.

Implications for practice

- Be aware that older women may not have a next of kin or partner to support them during their mesothelioma journey and address this within the package of care and support provided
- Ensure that sufficient time is available to support people in understanding their diagnosis
- Some patients may require ongoing support to understand their diagnosis, especially if the diagnosis is unexpected or the patient has no prior knowledge of mesothelioma or asbestos exposure
- As more women reported that the explanation of mesothelioma was not given in an understandable way, there is an indication that women are more likely to require additional time and support to understand their diagnosis

Key finding 4 - Men and women's roles within the family and society influenced how they coped with a diagnosis of mesothelioma

The patient's role within the family can provide an indication of what may be important to them during their mesothelioma journey. For our participants in intimate relationships, many households had a fairly traditional distribution of gender roles. This included women who did the majority of the emotional care-giving and housework, and men who were responsible for the financial care-giving and DIY. For both men and women, fulfilling these roles allowed them to maintain a sense of identity. However, some women expressed frustration at the consequences of their gendered role within the family:

"Because [my father's] clothes were always covered in dust and that when he came home. I used to do the washing for my mum 'cause she was ill on and off. We used to shake the powdery stuff off the clothes outside the back door and then wash them...So it was a bit of a hard life really and I really didn't get any relief until…it's wicked to say, I loved my parents dearly, but I didn't get any relief until they both passed on...Then a few years after they'd gone, I end up with this. That's what makes me angry when I think about it."
F6 Fiona

Participants also had concerns about who would fulfil these roles after they had passed away. These concerns meant that participants prepared their loved ones in different ways:

"I took down the net curtains, because I said well, men don't wash net curtains... I put up blinds everywhere." **F1 Amy**

"I do all the bills, I do everything in the house as far as the running of it, if you like. So I've got to try to start getting her to do all the banking, all the money, all the bills, that part of it."
M4 Derek

Not being able to fulfil these roles because of their illness had a significant impact on participants' sense of identity. Conversely, maintaining these roles as much as possible helped maintain their sense of identity, and provided purpose and continuity during an otherwise uncertain and disruptive time.

In addition to the participants' gender, their age, occupation and living circumstances also influenced how participants coped with their diagnosis of mesothelioma. For example, a female participant, who worked in statistics, required quantitative information about their prognosis to feel calm. Similarly, for a male participant

who was a clergyman, activities such as spending time with parishioners, choir competitions and holding services helped him to cope with his diagnosis of mesothelioma. For these participants, fulfilment of these roles gave them a sense of purpose that was important for their mental well-being.

In this sense, it is often the intersection of gender and other aspects of identity (such as social role related identity) that is important when considering patient needs.

Implications for practice

- Consider the patient's role within the family and society, and how this may impact on their priorities whilst living with mesothelioma. These priorities may impact on how they choose to prepare for their family's future and what helps them to cope with their diagnosis
- Patients' occupations may provide contextual information about their care needs. A patient's occupation may also form an important part of their identity. Therefore, ensuring that they can continue in this role may help them to cope with their diagnosis of mesothelioma

Key finding 5 - No significant gender differences were reported in treatment and care experiences following diagnosis

As noted in the introduction, GEMS aimed to focus on the similarities (as well as the differences) in the experiences of men and women living with mesothelioma. This key finding, highlighted by the quantitative data in Table 4, suggests that there were no statistically significant differences found between the treatment and care received by men and women. The interviews seem to support this view as there were no notable accounts of differences relating to treatment and care. Participants also provided several examples where health care professionals had delivered excellent care which considered the individual needs of the patient.

"…my [Meso UK nurse specialist] is a lovely person, really lovely and very welcoming." **F3 Cath**

"I think the NHS is excellent now…when someone presents with something that they can't determine it seems that there's consultation between specialist departments at different hospitals and their centres of excellence." **M3 Callum**

"He was great. Mr [consultant] I really, really like because I think he respects the fact that I need knowledge" F7 Grace "…both specialists, Mr [consultant] and Mr [consultant 2], gave us enough time, so we were lucky in that way." **M12 Lenny**

This is a positive finding as it suggests that, overall, treatment and care is patient-focused and tailored to meet the needs of the individual, no matter what their gender.

However, there are some important points and limitations to note here. First, the differences noted in respect of treatment and care, while not statistically significant, may still be important. For example, that 5 per cent more men reported failure to control breathlessness may warrant attention in clinical practice, as might the finding that 9 per cent more women reported failure in controlling coughing. Secondly, while not directly linked to gender, it is important to note that coughing and fatigue seem to be symptoms that are not so well managed (for men and women) and this is an important finding for clinical practice. Finally, some differences, such as whether the diagnosing doctor had sufficient knowledge of their condition, become more marked when considering the specific type of mesothelioma – 60 per cent of women (compared to 33 per cent of men) with peritoneal mesothelioma believed that their diagnosing doctor lacked sufficient knowledge.

"[At diagnosis] he did have to say on many occasions, this is not my expertise, this is not my expertise." **F4 Donna (living with peritoneal mesothelioma)**

Implications for practice

- Encourage healthcare professionals to continue to provide patient-focused, individualised care

Treatment-related Question	Men		Women		p-value
	Yes (%)	No (%)	Yes (%)	No (%)	
1.47 Satisfied with Treatment (Y/N) Overall have all the professionals involved in your treatment worked well together to provide the best possible care?	84.4 %	14.5%	87%	13%	P=0.3
1.28 HPs had Sufficient Knowledge (Y/N) Do you think that the doctors treating mesothelioma knew enough about the condition and treatment?	87.9%	12.1%	83.8%	16.2%	P= 0.4
Symptoms Management by Gender					
Q1.30. Breathlessness Controlled (Y/N) Did hospital doctors and nurses do everything they could to help control any breathlessness?	70.2%	35.1%	64.9%	29.8%	P=0.5
Q1.31. Fatigue Controlled (Y/N) Did hospital doctors and nurses do everything they could to help control any fatigue?	51.1%	48.9	47.8%	52.2%	P=0.7
Q1.32. Coughing Controlled Did hospital doctors and nurses do everything they could to help control any coughing?	55.3%	44.7%	46.2%	53.8%	P=0.4
Q1.33. Pain Controlled Did hospital doctors and nurses do everything they could to help control any pain?	79.2%	20.8%	77.5%	22.5%	P=0.8

Table 4: Treatment and care experiences P<.05

- Explore ways to improve the management of coughing and fatigue. This may be beneficial for all patients
- Ensure that people receiving a diagnosis of peritoneal mesothelioma have the opportunity to discuss their diagnosis with doctors who have sufficient knowledge of the condition

Key finding 6 - Men and women had different ways of communicating with professionals along the mesothelioma pathway

Differences in communicating with professionals were found in the analysis of the interview data. These gendered differences in communication influenced how treatment, trials and support were discussed and requested.

When expressing decisions about treatment and trials, our male participants used more direct language and appeared confident in their decisions. In contrast, the women appeared more tentative and uncertain in communication regarding treatment and trials:

"I'll be telling them to stick their chemo where the sun doesn't shine and I will carry on being well and look after myself." **M8 Ivan**

"I know I had… I think… Whether it was that first time… I wasn't sure whether I wanted to go ahead and have chemotherapy, which was suggested. I wanted time to think about it." **F3 Cath**

Both the above participants decided to have chemotherapy but the expression of the decision differed. The confident and clear way in which men expressed their decisions about treatment was less evident when they recounted discussions around emotional support:

"I have been doing that [talking therapy]. I just, I find that, I'm not sure whether I find it helpful or not…last week or the week before, I said to him [the therapist] towards the end…I'm really not sure why I'm here and I'm, what I'm getting out of this." **M2 Ben**

When recounting discussions around emotional support needs, the women interviewed appeared to be more forthright than the men interviewed:

Interviewer: "So you were given the opportunity for...support groups?
F5 Edna: "Oh God no, I don't want that. It has been offered."

These findings suggest that care should be taken not to assume that decisions and needs expressed are final. Patients may talk in a way that they consider socially acceptable when discussing decisions regarding treatment, trials and support needs. However, after consideration and time reflecting on options, initially expressed preferences may change.

Implications for practice

- Offering information and support throughout the patient journey may encourage patients to express their needs and help staff identify any change in patients' needs over time
- Patients may need time to reflect before making a decision and then communicating it to their healthcare professionals. Providing frequent opportunities for patients to discuss their treatment and care options may also facilitate open and honest communication

Key finding 7 - Preferences for the types of support desired showed some differences between men and women

Both men and women appreciated person-centred care that focused on their individual support needs. Having people present and available to provide support was valued by all participants. However, the data showed that men and women fell broadly into two camps in terms of preferences for type of support. Women more often expressed a preference for support where they have opportunity to talk, are listened to and feel heard:

"I went, to be honest I've just phoned up [a charity helpline] to rant to somebody who's not related to me, who doesn't know me and somebody where I can put the phone down." **F4 Donna**

In contrast, men tended to express a preference for practical support; like the provision of information, having meals cooked and having help with domestic tasks:

"...the support that we had from friends, family, local church, everything, it was amazing, which kind of helped. You knew you had…a quote is, an army of people...an 80 year old was doing our ironing. People sent us vouchers for meals. Yeah, it was amazing." **M12 Lenny**

It is important to note that ASGs played a key role in providing men and women with these opportunities to talk, be listened to, and receive and share information. Non-verbal support was highlighted in the men's interviews. Several men discussed the importance of having people around and available - but not necessarily talking directly about the impact of mesothelioma. This was in contrast to the women's need for verbal communication support, discussed above:

"I was really careful about who I wanted to come and see me [in hospital]...you've got certain friends that will come up and they are incredibly supportive and understanding and empathetic without even saying anything. And there's one particular friend, who I love to bits, but all she would do is gawp and touch you on the arm and go, oh, you alright? Well, I don't need that; I don't want that." **M8 Ivan**

Knowledge of peoples' preferences for support can help health and other professionals to provide patients with appropriate individualised care.

Support groups provided an opportunity for participants to share experiences with others living with mesothelioma. Experiences were shared around treatment, trials and compensation. They also provided participants, both men and women, with opportunities for discussing their emotions. In contrast to the general view (noted above) of men only requiring practical support, the following example highlights the important role of a men's only support group in enabling Jude to express his emotions in a way that he had previously felt unable to:

"I was quite a private person and kept my worries to myself but going to this men's [cancer support] group on a Friday

afternoon it encouraged me to speak more about my fears and my problems [...] it gets quite tearful at times when you're speaking about different things." **M10 Jude**

Not all participants attended support groups. Some participants felt that they were not useful for them. However, often there were discussions of other sources of support e.g. online groups, Facebook groups, etc, that participants did find useful. This suggests that providing the right environment and a range of support options can be helpful and important.

Implications for practice

- Provide a range of options so that people can access the support that they consider appropriate. This may include single-sex support groups or smaller support groups with less people attending
- The move towards online communication since COVID-19, means that there may be additional opportunities to provide and evaluate support being provided in new and creative ways e.g. discussion boards, smaller groups, single sex groups, breakout rooms

Key finding 8 - Men were more willing than women to pursue civil compensation

Findings from the HASAG data indicated that there were differences between men and women regarding being awarded the Industrial Injuries Disablement Benefit and pursuing civil compensation. It was found that:

- 11.6 per cent of women did not receive Industrial Injuries Disablement Benefit award compared to only 3 per cent of men
- Survival analysis found that time from diagnosis to receiving the Industrial Injuries Disablement Benefit was shorter for men than for women (43 vs 47 days) (p=0.01)
- Women were less likely to seek legal advice (60 per cent women vs 80 per cent of men) and less likely to receive compensation
- Women were less likely to want to seek legal advice than men (35 per cent of women vs 18 per cent of men expressed the view that they were not interested in receiving legal advice)
- There were differences in how many men and women actually went on to seek legal advice over the three year period that these figures were considered. This figure dropped particularly rapidly for women. For men it dropped from 87 per cent to 75 per cent over the three years. For women it dropped from 70 per cent to 51 per cent

The greater number of men wanting to seek legal advice and actually seeking legal advice may be linked to a sense of responsibility for the financial security of the family. Men may also be encouraged to seek compensation if they work in a high risk occupation for asbestos exposure. This data also suggests that some men may be more likely than women to believe they have a right to claim. The findings from the interviews indicated that male participants often felt a sense of financial responsibility to their family, and also a greater sense of entitlement to compensation. This may be linked to more awareness and experience of mesothelioma through their occupations (see key finding 2). Seeking compensation was therefore important to them:

"I deserve that and I should have that and I want as much as possible. And the reason I want that is, not for me to spend because I've got enough myself, but for when I'm not here that the family is well catered for." **M8 Ivan**

In contrast, the women participants were more likely to be deterred from seeking civil compensation. This appeared to be due to social expectations.

> 'The data suggested that women did not want to be perceived as financially motivated and also wanted to avoid confrontation.'

The emotional burden on their families also possibly acts as a deterrent for women seeking civil compensation (even though receiving compensation might relieve financial burden for their family):

"I didn't want to come across as being greedy." **F4 Donna**

"I don't want to fork out for a solicitor to try and delve into a lot of stuff for them to turn around and say, actually I can't get anything." **F4 Donna**

"I just feel it [seeking civil compensation] could have been quite acrimonious and unpleasant..." **F9 Irene**

The quotes above suggest a belief that seeking compensation is too costly, time-consuming or will make the experience of living with mesothelioma more challenging than it already is.

This key finding highlights that differences exist in the number of men and women seeking and receiving the Industrial Injuries Disablement Benefit and civil compensation. Data suggests that the reasons for this are complex but may include familial responsibility, social perception and preconceived ideas of what the process of seeking compensation will entail.

Implications for practice

- When having discussions with people living with mesothelioma, ASG professionals, solicitors and nurse specialists should explore reasons why individuals are not seeking compensation
- Fear of cost and an acrimonious process could be dispelled by providing information of civil claim case studies. Additional time and support to address these concerns could be built into service provision
- Further research into why people choose to pursue compensation or not would be beneficial for healthcare, ASG and legal professionals advising people living with mesothelioma and their families

Conclusion

The mixed-methods GEMS identified gender differences in diagnosis experiences, and support needs and preferences for men and women. Several motives led to the development of GEMS. These included emerging evidence of sex differences in mesothelioma and indications of differences in men's and women's experiences of asbestos exposure and living with mesothelioma. GEMS has provided evidence of differences in the experiences of men and women living with mesothelioma in the UK.

There were many examples of how men and women's mesothelioma journeys may differ. These included perceptions of risk of mesothelioma prior to diagnosis, classifications of high risk occupations, preferences for types of support and motives for seeking financial compensation. Satisfaction with treatment and care following diagnosis was highlighted as a similarity for both men and women. This suggests little evidence of gender inequalities in patient perspectives of mesothelioma treatment and care in the UK.

Several implications for practice have been presented. There were three key areas in which implications for practice were developed. These focused on improving awareness of the dangers of asbestos, offering support and information which considers gendered differences, and exploring the barriers to seeking benefits/ compensation for women and men.

Asbestos is still contained in many work settings and buildings across the UK. It is an employer's duty to ensure safe working conditions (Pickles, 2018). The development and implementation of asbestos safety guidelines which can be used in occupations and workplaces across the UK may lead to better protection for staff and increased knowledge of how to avoid asbestos exposure. This may include information giving as part of mandatory training for staff working in environments where asbestos is likely to occur e.g. schools and hospitals built when asbestos was commonly used as a building material (Allmark & Tod, 2020).

At different points of the mesothelioma journey, women and men may require different types of support and information. Considering the prior level of knowledge and experiences with asbestos and mesothelioma is important for professionals to take into account when assessing the support and information that may be required. The additional challenges that women may face accessing benefits and seeking compensation may mean that they are not always receiving their full entitlement in a timely manner. Understanding these reasons for not wanting to, or not being able to claim benefits or pursue a civil claim, requires further exploration, both in practice and future research.

These implications have been designed to support the practice of healthcare, ASGs and legal professionals working with people living with mesothelioma and their families. Going forward, it is hoped that the findings and implications for practice contained in this report will improve the care provided to women and men living with mesothelioma.

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