

The Gendered Experience of Mesothelioma Study (GEMS)

12 Kings Bench Walk International Women's Day Webinar
12th March 2021

Professor Angela Tod, Dr Steven Robertson, Dr Michaela Senek, Dr Bethany Taylor and Dr Stephanie Ejegi-Memeh
Division of Nursing and Midwifery, School of Health Science
University of Sheffield

Contact: s.ejegi-memeh@sheffield.ac.uk

The Gendered Experience of Mesothelioma Study (GEMS)

Why focus on the gendered experience?



Aim

To explore men and women's experience of mesothelioma in order to understand similarities and differences e.g. awareness of mesothelioma, risk and exposure, presentation and diagnosis, access to treatment and compensation and legal processes



Project summary

Design

Stage 1: Statistical analysis of national data

Stage 2: Qualitative interviews and analysis

Stage 3: Testing out the findings with key stakeholders and focus groups

Today's presentation



THE DEFINITIVE GUIDE TO RELATIONSHIPS

MEN ARE
FROM MARS,
Women Are
from Venus

JOHN GRAY

OVER 15 MILLION COPIES SOLD WORLDWIDE



HASAG data set



- Cases from 2016, 2017, 2018.
- 1177 mesothelioma cases
 - 82.5% were men (971)
 - 17.5% were women (206)

HASAG data findings

- **Age** - Both men and women are in mostly in the 71-80 year group at diagnosis. (42% vs 44%).
- There are more very young women in the cohort (5% of women are under the age of 50 compared to only 0.5% of Men).
- **Next of Kin** - Fewer women had a next of kin (75%) vs men (82.5%).
- Fewer women had a spouse/partner (46% vs men 63%).
- **Type of mesothelioma** - Majority of cases were pleural (99%) and 1% of cases were peritoneal.
- Women were more likely to have peritoneal (4% of women vs 1% of men).

Proportion who said they are **Going to Call** and **Called** a Solicitor (3 years).

Men:

89% → 87%

82% → 79%

77% → 75%

Women

80% → 70%

63% → 58%

53% → 51%

What does it mean

- Percentage of both men and women who are *Going to Call* decreases over the 3 years
- The trend is same for men and women
- Number of men has dropped by 12% vs 27% women.
- The % of Women who seek legal advice has dropped by nearly 20%.

Occupational Risk

- Our findings show that the high risk population for Men is Construction (*Carpenter, Joiner, Plumber, Electrician*) whereas high risk occupation for Women is *Admin, Teacher, Health Services*.
- For women, admin is the High Risk Occupation in this data set (29%), health services (nurse/lab), (10%), teacher/school (10%), Retail (6%), Factory (7%).





Interview participant demographics

11 women and 13 men

- Age: 31-79
- Living circumstances: Single, living together, divorced, married
- Location: Across England and Scotland
- Length of time living with mesothelioma: 5 months – over 5 years
- Occupation

Being practical at diagnosis



“My response to my diagnosis was to come home and to chuck everything out, and I took down the net curtains, because I said well, **men don't wash net curtains** [...] I bought everything new, so when I was gone there was nothing he had to buy.” 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

Control and treatment

“I’m happier sort of being told what to do. I’m not very good at making decisions” F3, Cath

“my quality of life is more important. So 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

Risk perception



“Interviewer: And what about when they started asking questions in the hospital about asbestos exposure? How did you feel about that?”

Fred: A sort of **inevitability**” M6, Fred

“R: Somebody said to me, have you worked with asbestos, and I said no ‘cause I thought, well what a **stupid question** really, you know? I would never have dreamed that I would have got it” F6, Fiona

“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




Seeking compensation


“I wasn’t 100 per cent convinced in my own mind that a previous employer had actually caused my meso and I didn’t really feel I had a grievance against them.” F9, Irene

“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


Key points from the data




- The importance of a sense of control at diagnosis may differ between men and women. This difference may have implications for patient priorities and the delivery of health care



- Women and men may have different priorities during their mesothelioma journey e.g. treatment trials and finances.



- Women may lack awareness of the risk of exposure and asbestos related diseases. The nature of exposure to asbestos may be different. Therefore, we may need to consider occupational risk differently for men and women.



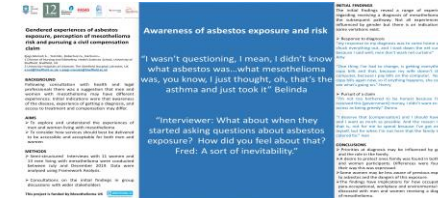
- Women may be less likely to seek compensation. This could be due to lower awareness amongst women and a higher sense of entitlement amongst men.

What next?

Sharing GEMS findings Presentations



Posters



Publications and reports





MESOTHELIOMA UK

Supporting People With This Asbestos Cancer

Mesothelioma UK Research Centre - Sheffield

Established in 2020, the Mesothelioma UK Research Centre - Sheffield conducts a portfolio of robust and rigorous research with a reputation for excellence nationally and internationally.



Led by Professor Angela
Tod and Dr. Clare
Gardiner

Launched
November 2020



The Vision

The **Mesothelioma UK Research Centre** will conduct a portfolio of robust and rigorous research with a reputation for excellence nationally and internationally

Projects

- Rapid review of evidence on mesothelioma patient and carer experience
- Mesothelioma and schools/education
- Peritoneal mesothelioma
- Impact of COVID on patients and staff
- The Experience of Long-term Survival in People Affected by Pleural Mesothelioma and Their Carers. (Matt)
- **Research prioritisation exercise**

Please contact us for:

1. Research ideas
2. To participate in the Research prioritisation exercise
3. To be in contact with the Mesothelioma Research Centre – Sheffield

a.tod@Sheffield.ac.uk; c.gardiner@Sheffield.ac.uk

Thank you for listening

12 Kings Bench Walk International Women's Day Webinar 12th March 2021

Professor Angela Tod, Dr Steven Robertson, Dr Michaela Senek, Dr Bethany Taylor and Dr Stephanie Ejegi-Memeh

Division of Nursing and Midwifery, School of Health Science

University of Sheffield

Contact: s.ejegi-memeh@sheffield.ac.uk