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Proceedings Paper:

Tod, A. orcid.org/0000-0001-6336-3747, Darlison, L., Ejegi-Memeh, S. et al. (2 more authors) (2020) The Gendered Experience of Mesothelioma Study (GEMS) : initial findings from a mixed method study. In: Lung Cancer. 18th Annual British Thoracic Oncology Group Conference 2020, 29-31 Jan 2020, Dublin, Ireland. Elsevier , S69-S70.

[https://doi.org/10.1016/s0169-5002\(20\)30188-4](https://doi.org/10.1016/s0169-5002(20)30188-4)

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Tod A, Darlison L, Ejegi-Memeh S, Robertson SR, Senek M

Lung Cancer 139:S69-S70 Jan 2020

DOI: [https://doi.org/10.1016/S0169-5002\(20\)30188-4](https://doi.org/10.1016/S0169-5002(20)30188-4)

The Gendered Experience of Mesothelioma Study (GEMS): Initial findings from a mixed method study

Background

Following consultation with health and legal professionals there was a suggestion that men and women with mesothelioma may have different experiences. Initial indications were that awareness of the disease, experience of getting a diagnosis, and access to treatment and compensation may differ.

Aim

GEMS aims to explore the experiences of men and women with mesothelioma in order to understand any differences that are identified and how services should best be delivered to be accessible and acceptable to both men and women.

Methods

A mixed methods study comprising:

1. Secondary analysis of data from an Asbestos Support group (HASAG). Anonymized data from 977 people who accessed HASAG over 3 years (2016-18) were analysed.
2. Semi-structured interviews with 10 people who have a diagnosis of mesothelioma and their family carers. Thematic analysis was used to identify key themes.
3. Consultation on the emerging findings in group discussions with wider stakeholders e.g. NHS, Asbestos Support Groups, charities.

Findings

Emerging findings reveal a range of experiences regarding receiving a mesothelioma diagnosis and the subsequent pathway. These are not always influenced by gender. However, there is an indication from all data that some variations exist, for example in time from symptom to diagnosis. Women with pleural mesothelioma take longer to diagnose than men, whilst men with peritoneal mesothelioma take longer to be diagnosed than women. The study also provides insight into the gendered nature of occupational history taking, the impact of mesothelioma on identity and the family, and action regarding pursuing a compensation claim.

Conclusion

This novel study provides insight into how men and women's experiences of mesothelioma varies. Quantitative findings indicate where variations exist whilst interview and consultation discussions provide potential explanations for those

variations. Recommendations are made regarding service provision especially regarding diagnostic decisions and occupational history taking.

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