

The psychological effects of mesothelioma in the UK military context from the carer's perspective

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Introduction

Mesothelioma is an incurable asbestos-related cancer with a high symptom burden. Risk of asbestos exposure to Armed Forces personnel has been identified, e.g., from ships' boiler rooms and damaged buildings. Mesothelioma's long lead time means cases in the military context tend to be amongst veterans. Research shows British veterans and their families are likely to have particular needs regarding accessing health services and support. Research into the lived experience of mesothelioma patients is sparse, with resulting lack of awareness of the psychosocial impact, on carers as well as patients. This study explored the psychological effects of mesothelioma in the UK military context from the carer's perspective.



Methods

This qualitative study involved:

- 1) a secondary data analysis (SDA) of interview data from the Military Mesothelioma Experience Study
- 2) six semi-structured interviews (September 2020-March 2021) with family carers of UK veterans with mesothelioma
- 3) interpretative phenomenological analysis.

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Findings

The findings provide insight into the psychological impact on veterans and their carers. Themes developed included 'Going the extra mile'; 'Staying the same person'; 'Needing to know'. Military culture impacted both patients and carers.

See Table 1 for a summary of themes developed.

Table 1: Summary of themes

| Stage of study | Super-ordinate themes | Subordinate themes |
|-------------------------|------------------------------------|---|
| Secondary data analysis | Control and responsibility | The chain of command |
| | | Controlling language and thinking |
| | | The out-of-control body |
| | | The proactive carer |
| | Openness: is it safe? | Secrecy and intimacy |
| Main interview study | Human connections: getting support | Official secrets |
| | | Becoming vulnerable |
| | | (No subthemes) |
| | | |
| | Going the extra mile | Just keeping on going |
| | Staying the same person | Expecting and receiving committed back-up |
| | | The recognisable patient |
| | | The recognisable carer |
| | Needing to know | Choosing what to share |
| | | Information exchange and professionals |
| | | Raising awareness |

Conclusions

Issues highlighted include:

- military veterans' and their carers' responses to pain from a terminal illness
- reluctance to show perceived weakness and ask for help affecting both patients and carers
- moral injury relating to carers' interactions with the MOD and the NHS

