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Why you should read this article:

- To increase your awareness of the effects of mesothelioma on veterans and their family caregivers
- To recognise the positive and negative influences of a military background on veterans' and their caregivers' experiences of mesothelioma
- To appreciate the need for sensitive, skilled and honest communication when discussing diagnosis, prognosis and care interventions with veterans with mesothelioma and their caregivers

Mesothelioma: exploring psychological effects on veterans and their family caregivers

Virginia Sherborne, Angela Tod and Bethany Taylor

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Abstract

Background: In the UK, around one in eight adults aged over 65 years is a veteran of the UK armed forces. There is little research into the experiences of veterans with mesothelioma and their family caregivers.

Aim: To explore the psychological effects of mesothelioma on UK veterans and their family caregivers from the caregivers' perspective.

Method: Purposive sampling was used to recruit six participants to this qualitative interview study. Individual semi-structured interviews were conducted and data were analysed using interpretative phenomenological analysis.

Findings: There was an underlying influence of the military background on several facets of caregivers' and veterans' experiences. Veterans and caregivers made efforts to 'just keep on going'. Psychological benefits were derived from having a stoic outlook, retaining one's sense of humour, being goal-oriented and putting others first. Holding to high military standards such as loyalty led to broken trust and anger. Straightforward 'need to know' communication is a priority in the armed forces and this also influenced caregivers' and veterans' experiences.

Conclusion: It is important that nurses are aware of the specific cultural factors present in armed forces veterans and their caregivers so that they can assess and address their needs adequately.

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Keywords

cancer, carers, families, mesothelioma, patient experience, patient psychology, patients, professional

Background

Around one in eight adults over the age of 65 years in the UK is a veteran of the UK armed forces (Brewster et al 2021). A veteran is a person of any age or gender who has previously served in the armed forces, whether as a regular or a reserve member (Ministry of Defence 2022). Until leaving the armed forces, many veterans will not have lived as civilians since they reached adulthood and may therefore be unfamiliar with services such as the NHS. Older veterans may be reluctant to seek medical support because they pride themselves on their self-sufficiency (Williamson et al 2019). Veterans and their families tend to have specific needs in relation to healthcare (Hynes and Thomas 2016).

Mesothelioma is a type of cancer that develops in the lining of the outer surface of certain body organs, mainly the lungs. It

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cannot be cured, and the aim of treatment is symptom control. Mesothelioma, which is usually linked to asbestos exposure (NHS 2022), has a high symptom burden and poor prognosis (Hoon et al 2021). The UK has the highest incidence of mesothelioma in the world (Ejegi-Memeh et al 2020). Potential sources of asbestos exposure specific to armed forces personnel relate to living accommodation, combat experiences and extensive travel (Ejegi-Memeh et al 2020).

Since mesothelioma takes 15-40 years to appear (Ejegi-Memeh et al 2020), instances of the disease among military personnel usually occur in veterans who are middle-aged or older. If they have been exposed to asbestos during service, veterans diagnosed with mesothelioma can apply for an upgraded pension or a one-off payment (Ministry of Defence 2016). Claiming for financial compensation can be particularly complicated and stressful if the claimant has been exposed to asbestos during service and in civilian life ('dual exposure') (Ejegi-Memeh et al 2020).

Patients with mesothelioma and their caregivers experience anxiety, depression and traumatic stress (Bonafede et al 2020, Hoon et al 2021). However, little is known about the experiences of veterans with mesothelioma, so there is insufficient awareness of the psychological effects of the condition on this patient group (Harrison et al 2021). Furthermore, there has been little research into the experiences of family caregivers of veterans with mesothelioma (Guglielmucci et al 2018). This lack of evidence prompted a group of researchers to conduct the Military Experience of Mesothelioma Study (MiMES) (Ejegi-Memeh et al 2020), which highlighted the distinct challenges faced by veterans with mesothelioma and their families.

This article presents the findings of a PhD-funded study conducted as part of the MiMES, which explored the psychological effects of mesothelioma on veterans and their family caregivers from the caregivers' perspective. The UK Armed Forces Covenant stipulates that those who have served should be treated fairly (Ministry of Defence 2022). This study may enhance nurses' understanding of the needs of veterans and caregivers and their ability to address those needs. The study may also help generate insight into living with an incurable condition and challenging symptoms.

Aim

To explore the psychological effects of mesothelioma on UK veterans and their family caregivers from the caregivers' perspective.

Method

This was a qualitative interview study using interpretative phenomenological analysis (IPA). IPA has been used frequently for researching illness experience (Smith et al 2009), especially to explore issues with a deep meaning for people, such as a terminal diagnosis.

Recruitment

Purposive sampling was used. Mesothelioma UK, regional asbestos support groups and veterans' support organisations disseminated information about the study on social media. Those interested in participating were asked to call the Mesothelioma UK helpline to obtain further information. They were then contacted by the researchers and sent a participant information sheet.

To participate, caregivers had to be:

- Aged 18 years or more.
- The main informal caregiver of a veteran with a mesothelioma diagnosis who was still alive or had died in the previous three to 24 months.
- Capable of giving informed consent.

Six participants were recruited. Two were daughters and the other four were spouses, one of whom was a veteran themselves. Participants were in their early 40s to late 70s and their relatives were in their late 40s to late 80s. Participants lived in England or Wales.

Data collection

Each participant took part in an individual semi-structured interview with the lead author (VS). To develop the interview schedule, VS drew on the literature about the lived experience of mesothelioma – including Ejegi-

Implications for practice

- Veterans and caregivers can be significantly affected by the style of delivery of diagnosis and prognosis
- Nurses need to be as sensitive as possible when breaking bad news and should receive adequate training to develop the relevant communication skills
- It is important that nurses are aware of the cultural barriers preventing veterans from reporting symptoms such as pain
- Caregivers with a connection to the armed forces may feel unseen and of less value than other caregivers, therefore nurses should ensure they feel included
- Caregivers' needs can change in the course of their relative's illness, so their needs should be assessed regularly

Box 1. Interview schedule

- Please could you tell me about your experience of being a carer for your spouse or parent with mesothelioma?
- Did you experience any changes in yourself as a person, either positive or negative? And in your spouse or parent?
- What were your coping strategies? And your spouse's or parent's coping strategies?
- Were there any ways that your spouse's or parent's military background influenced the effects of the illness on you and/or on them?
- Could you describe the effects of the illness on your mental health? And on your spouse's or parent's mental health?
- Did you experience any changes in your relationship with your spouse or parent? And/or with anyone else?
- Were there any ways that your support needs, and your spouse's or parent's support needs, could have been better addressed?
- If you had to summarise the most important points from what we've just talked about, what would you say?
- Is there anything else about this experience that you feel we haven't adequately covered yet?

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Memeh et al (2020) – and consulted patient and public involvement (PPI) representatives. Box 1 shows the interview schedule.

During the interviews, VS also used prompts and probes as needed, for example 'What was that like for you?', 'What did that mean to you?', 'Tell me more about…'

The interviews took place between September 2020 and March 2021 via an online videoconferencing platform and lasted between 58 and 115 minutes. VS and the participants did not know each other before the study. The interviews were digitally audio recorded and field notes were taken afterwards. Verbatim transcripts of the interviews were made and anonymised.

VS is an experienced qualitative researcher and a counsellor with expertise in trauma and bereavement. In the context of this study, VS held two statuses – she was a civilian (an 'outsider') and a lung cancer survivor (an 'insider'). To ensure self-care, VS accessed counselling for the duration of the study. To manage potential bias, VS practised narrative reflexivity and consulted PPI representatives at various stages of the study.

Data analysis

VS analysed the data following the six IPA steps (Smith et al 2009) in a rigorous immersive and iterative process aimed at developing themes. VS and the other researchers (AT and BT) met regularly to consider the themes' credibility and grounding in the data. A software programme was used for sorting and storage of data.

Ethical considerations

The University of Sheffield provided ethics endorsement. This covered issues such as obtaining written informed consent and avoiding harm to participants. UK Health Research Authority approval was not required as participants were recruited and the study was conducted without involving NHS staff or systems. Before each interview, VS explained to participants that their anonymity and confidentiality would be protected, and that the data would be published, and asked them to give written informed consent.

Findings

Three themes and seven subthemes emerged from the data analysis. These themes and subthemes are discussed below and illustrated by quotes from the interviews with the six caregivers, who have been given pseudonyms.

Going the extra mile

This theme covered how veterans and caregivers reacted to the diagnosis and prognosis, how they managed daily tasks and how they experienced other people's support.

Just keep on going

Veterans and caregivers made efforts to 'just keep on going' despite the poor prognosis, challenging symptoms, such as breathlessness, pleural effusion or fatigue, unpredictable disease progression and sudden deterioration. Having a stoic outlook enabled some veterans to feel in control and self-reliant. Four participants made sense of this in terms of their relative's military background:

'He never really left the military. He was always sort of "Stand by your beds!". Quite stoic, and I guess probably some of that did have an impact on how he dealt with the prognosis. "Bloody nuisance, this" and "Crack on!".' (Nicola about her father Len)

'It affected the way he coped with his illness in a positive way, in that he just got on with it. […] but then in a negative way because he was not very good at flagging up that he needed help.' (Julie about her husband Dave)

Some caregivers were negatively affected by the veterans' stoicism regarding pain. Cerys felt anxious because she was aware that her father Hywel attempted 'not to give in to pain relief'. Vicky was shocked when her husband Mike, who strongly believed in 'the power of the mind' to cope with pain, rejected the offer of a syringe driver.

Five participants described how a strong need for independence – either their own or that of their relative – had negative psychological effects on them, since asking for outside help was not acceptable. Vicky felt as if she 'hit a brick wall' trying to manage all her husband Mike's care herself, at his insistence. Gary felt ashamed to have neglected his own well-being because he wanted to be constantly 'on duty' beside his wife Marie:

'I'm totally unhealthy now, I've got about five stones that I don't need.' (Gary)

Expecting committed backup

In the armed forces teamwork, selflessness and loyalty are highly prized, which may partly explain why veterans and caregivers expected to receive committed backup from others. When they received optimal support they felt relief, hope and gratitude. One of the caregivers, Janet, had many supportive visitors to whom she talked openly; for example, she expressed her fears about widowhood and was reassured by her granddaughter's caring

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response. Cerys found a little hope when she encountered, at a support group, people who had been living with mesothelioma for more than three years after diagnosis.

When the veterans' and caregivers' expectations of support were not met, they felt angry and abandoned. Gary was angry when long-term friends simply disappeared. Janet's husband Arthur was 'really, really upset and it really got him down' when a healthcare appointment was cancelled without notice. Julie was disappointed by her GP:

'I've had no direct contact, no follow-up really.' (Julie)

Staying the same person

The focus of this theme was on identity issues and how mesothelioma changed the ways veterans saw themselves and others saw them. There was often a clear underlying influence of their military background. Psychological benefits were derived from a stoic outlook, humour, being goal-oriented and putting others first. However, holding to high military standards such as loyalty sometimes led to broken trust, resentment and despair.

The recognisable patient

Caregivers did not consider that their relative had fundamentally changed as a person. They often mentioned, for example, that their relative had retained their thoughtfulness towards others. This was the case with Nicola's father Len.

Retaining one's sense of humour was valued as a coping strategy:

'It was really important to him. He was still making nurses laugh the day before he died and I'm really proud of that.' (Julie about her husband Dave)

Veterans were negatively affected by the fact that they could not remain unchanged. Janet's husband Arthur was uncharacteristically angry after undergoing surgery. Cerys' father Hywel experienced symptoms that made him less physically able, but he was averse to recognising this. That head in the sand attitude caused frustration for Cerys when trying to plan ahead:

'He'll say, "I'm concentrating on trying to live, not bothered about dying".' (Cerys about her father Hywel)

Two caregivers were in midlife and looking after their spouse, which appeared to add complexity due to their spouse's feelings about shifting roles. Gary explained that his wife Marie 'didn't want to look vulnerable' and was unhappy that her husband was becoming her caregiver. Julie said that her husband Dave wanted to 'sweep all those potential issues under the carpet.'

The recognisable caregiver

Two caregivers were daughters looking after their fathers, and both had experience as healthcare professionals which gave them confidence in their caregiving role. They viewed themselves as changing between roles while remaining their familiar selves, but sometimes felt that they were slipping out of role:

'You hold it together. But in between I've had my odd moments when I think, "Oh! This is my dad!".' (Cerys)

Another two caregivers, both wives looking after their husbands, worried about whether they would be resilient enough, since they had previously experienced mental health issues. Vicky was concerned she would become depressed again and 'not want to get out of bed'. Janet was uneasy about the way her mind operated under stress:

'[It's] like a washing machine. It's just going round and round.' (Janet)

The two middle-aged caregivers described unsettling changes in themselves. Julie noticed that she no longer trusted people as much. Gary, who was a veteran himself, felt that his military standards had slipped because he was less bothered about his work and maintaining a smart appearance:

'That's not me at all, but I don't care anymore.' (Gary)

Needing to know

This theme covered information sharing within the inner circle of family and friends, the exchange of information with professionals and the desire to raise awareness about the risks of exposure to asbestos. In the armed forces, straightforward 'need to know' communication is a priority and this influenced caregivers' and veterans' experiences.

Choosing what to share

Military culture influenced what caregivers and their relatives expected regarding information sharing with each other. This led either to secrecy, for example about pain, or to transparent communication as a component of teamwork and planning.

When the veteran's and their caregiver's approaches to information sharing matched, they experienced connection and safety. Janet explained how she and her husband Arthur felt emotionally closer. Gary and his wife Marie discussed 'absolutely everything' – although in fact she was concealing her pain levels

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from her husband. Nicola and her father Len talked openly about his impending death by using a metaphor:

'He chose from the start that he was going to "the Caravan Site in the Sky".' (Nicola about her father Len)

This helped Nicola and the care team plan Len's care proactively.

When there was a mismatch in people's approaches to information sharing they experienced isolation, frustration and distress. Vicky found it 'really hard' that Mike, who was used to keeping high-level military secrets, was unwilling for anyone to know about his condition. Julie felt that her husband Dave wanted to protect her:

'I felt Dave withdraw from me… because he was afraid, but also he didn't want to scare me.' (Julie)

Information exchange with professionals

Assumptions concerning information exchange with professionals – such as honest communication and attention to people's feelings – were influenced by the military background. If their assumptions proved correct, veterans and caregivers felt reassured and supported. Nicola and her father Len valued the GP's empathy, honesty and avoidance of making promises. Cerys valued the opportunity offered by a palliative care nurse to discuss pain management and medicines. Asbestos support groups were often mentioned as useful for making contacts and providing expert advice and support.

If their assumptions proved to be incorrect, veterans and caregivers felt anger, frustration, helplessness and traumatic stress. Vicky struggled with the instructions from healthcare professionals regarding Mike's care:

'I felt like a little hamster on a wheel, trying to catch up with the pain control.' (Vicky)

Janet and her husband Arthur experienced a mismatch in their need to know about his prognosis. A doctor they had never seen before broke the news that Arthur had one year left to live. Arthur, with his military instinct to plan, had asked directly: 'How long?' Janet, who was not ready to hear the answer, could not 'unhear' it and it had a traumatic effect on her.

Gary, expecting military-style teamwork and communication to apply to the NHS, felt let down and disappointed. He had imagined that staff would admit to mistakes in a no-blame process but found that this was not the case. Gary and Julie both felt let down by how the armed forces handled the issue of asbestos exposure and mesothelioma, both in their spouse's case and in general. Gary was shocked at the Ministry of Defence's attitude to his wife Marie's financial claim:

'They just lied to me each time.' (Gary)

Raising awareness

This subtheme arose from the accounts of the four caregivers whose relatives had died by the time of the study. These bereaved caregivers were keen to raise awareness among healthcare professionals, the public and the armed forces of the risks of exposure to asbestos. Their goal was to enhance understanding of mesothelioma symptoms and of the population groups affected by the condition. They wanted to proactively take a 'lessons learned' approach with the aim of improving communication and protecting others. Julie particularly wanted to highlight that younger people who had not worked in heavy industry or served in the armed forces could be affected through environmental exposure, for example because of inadequately maintained school or hospital buildings.

Discussion

Pain and the militarised body

Pain is a major symptom of mesothelioma and increases the burden on patients and caregivers (Hoon et al 2021). The study found that both the veterans' and their caregivers' responses to pain were influenced by their military background. Veterans may tolerate intense pain without seeking help (Engward et al 2018). Hitch et al (2020) identified that help-seeking among veterans could be hampered by pride and that their use of humour as a way of coping with pain could prevent healthcare professionals from identifying their needs, for example in relation to pain management.

All participants referred to the fact that their relative's pain was sometimes challenging to control. Having to manage medicines at home can put great pressure on caregivers (Wilson et al 2021). Furthermore, caregivers who identify closely with military customs may experience shame when they fail to maintain their physical fitness. Caregivers of veterans tend to de-prioritise their own well-being, with negative implications for their psychological health (Royal British Legion 2021).

After their time in service, veterans often keep exercising. Maintaining a highly-trained militarised physicality and remaining physically active can be important aspects of their transition to civilian life and their retirement (Grimell 2019, Williamson et al 2019). Older patients with mesothelioma are less likely to receive active treatment than younger patients (Warby et al 2019, Freudenberger and Shah

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2021), which may leave older veterans feeling that they have been 'written off'. This can be counterbalanced by offering rehabilitation, which encourages physical fitness, self-management of symptoms and social interaction, and can benefit patients from diagnosis onwards (NIHR Applied Research Collaboration South London 2019).

Influence of secrecy and comradeship

The study showed a wide spectrum of how veterans and their caregivers exchanged information. The military's inbuilt secrecy was mentioned by participants as an influence on people's habits regarding talking about emotions. Protective buffering – when a person avoids open communication to avoid distressing the other – is an approach employed by military couples coping with illness (Thandi et al 2017). This may have negative effects, such as feelings of isolation and worsening mental well-being (Thandi et al 2017).

However, comradeship within the military can be experienced as intensely intimate (Brewster et al 2021), so a couple can feel very close if the veteran views the spouse caregiver as on the same 'team' as them, enabling optimal adjustment and planning. This idea matches Thandi et al's (2017) message that veterans and their caregivers may overcome challenges by collaborating, viewing physical ailments as hazards 'to defeat together'.

Discussing prognosis and fostering hope

The study's focus on individual experience enabled the researchers to draw out differences in the way veterans and caregivers experienced mesothelioma. An important difference concerned their coping strategies and their desire for prognosis-related information. Veterans immediately engaged in a way of coping that focused on achieving tasks and solving issues. This matched the MiMES findings (Ejegi-Memeh et al 2021). The armed forces work by deploying a certainty-based frame of reference to handle unpredictable situations. When veterans find themselves faced with a life-threatening illness, task-oriented activities such as finding facts and making plans give them a sense of security. For civilians, however, an avoidant coping style may make more sense.

Lelorain (2021) researched how healthcare professionals could best discuss prognosis with patients diagnosed with cancer and recommended that they start by developing a rapport with the patient and assessing their information needs, avoid discussing the prognosis unless they already know the patient and postpone discussing the prognosis if the patient seems highly distressed. Healthcare professionals should also ask patients and family caregivers how much prognostic information they want. In a palliative care context, seeing patients and caregivers separately enabled healthcare professionals to meet different information needs (Swetenham et al 2015).

Taylor et al's (2019) study highlighted that, since breaking bad news can have lasting negative psychological effects on patients, a balance must be achieved in the communication of such information. The researchers also found that most participants preferred information delivered directly and honestly but also allowing hope (Taylor et al 2019). Henson et al (2019) showed that, among all patients with cancer, those with mesothelioma had the highest risk of suicide in the six months after diagnosis. Negative messages from healthcare professionals can result in hopelessness (Ball et al 2016, Girgis et al 2019). Fostering hope is important when giving a diagnosis of incurable cancer and is possible if couched in terms of achieving short-term goals, which may be particularly relevant for people with a military background.

Limitations

The sample size was small. However, IPA is designed to generate in-depth understanding from small samples, since it allows focus on individual nuance and since every participant brings a unique, useful perspective (Smith et al 2009).

VS's status as an 'outsider' may have compromised communication with participants. However, an outsider may take less for granted and participants from a masculinised military background may feel more comfortable talking about challenging topics with a female civilian researcher. VS's status as an 'insider' may have made it more difficult for her to stay open to different possibilities in the data but may also have brought deeper insight.

Recommendations for practice

The study findings can inform the practice of nurses who support veterans with mesothelioma – or other incurable cancers – and their caregivers. Table 1 summarises practice recommendations derived from the study findings.

Conclusion

Veterans of the armed forces and their families

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Table 1. Practice recommendations derived from the study findings

Military culture	Psychological effect on veterans and caregivers	Practice recommendations for nurses
Just keep on going, service before self	» Veterans feel in control and self-reliant » Caregivers try to manage without support, neglect their own health, feel shame	» Discuss the option of rehabilitation with veterans, framing it as a proactive way of enhancing physical performance and maintaining independence, and refer them as needed (Macmillan Cancer Support 2020) » Encourage communication between veterans and their caregivers, framing it as 'teamwork'; prompt veterans to view their caregivers as 'allies' who need accurate information to operate effectively; employing terms that resonate with military culture, such as 'teamwork' or 'allies', can be helpful » Remind caregivers regularly that they must look after themselves and that this will benefit their relative » Make caregivers feel included » Signpost to specialist information and support (for example, www.actionforcarers.org.uk/who-we-help/armed-forces-carers and www.mesothelioma.uk.com/armed-forces)
Being goal-oriented	Veterans and caregivers feel in control and maintain a sense of identity	» Proactively mention planning and achieving goals, including when talking about palliative care treatment options, as these concepts are likely to chime with veterans and their caregivers
Sharing information on a 'need to know' basis	Veterans and caregivers feel either reassured and supported or angry, frustrated and distressed	» Before disclosing a diagnosis or discussing a prognosis, determine how much information veterans and caregivers want; be ready for veterans to ask for a blunt prognosis; offer caregivers the opportunity to talk privately » Encourage veterans to report their actual pain levels, which can be framed as 'targeted information gathering' and can be undertaken using Mesothelioma UK's digital app Your Health Companion (www.mesothelioma.uk.com/your-health-companion) » Offer ongoing pain assessments to veterans » Periodically assess caregivers' psychological health and check whether they need support to manage care and medicine administration at home

tend to have specific needs in relation to healthcare, but there has been little research into their experiences of mesothelioma. This qualitative interview study shows that communication between family caregivers and veterans with mesothelioma may range from secrecy to transparency. It also indicates that a military background can have positive and negative effects on veterans' and caregivers' experiences. The study adds to existing research about how veterans cope with pain by exploring nuance within the patient-caregiver relationship. It also reinforces the importance of skilled and sensitive communication of diagnosis and prognosis in cancer settings and shines a spotlight on caregivers' needs.

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