

Analysis

Palliative and end-of-life care for military veterans:

the forgotten few?

BACKGROUND

Military veterans are likely to have encountered death, pain, and suffering, and to have prepared for them like few other groups in society. This is also a group trained to follow highly ceremonial rituals around death, burials, and commemoration. Yet veterans are not seen as 'different' in palliative and end-of-life care (EoLC), including that provided by GP practices. Throughout military service, encounters with death and dying are frequently intense, highly personal, and potentially traumatic, in ways seldom seen or understood in civilian life. Furthermore, the nature of military occupation — resembling more a lifestyle than a job — entails cultural separation from civilian life, with perceptions, norms, and ideals around death and dying forming part of this culture. Embodied experiences in military life as well as psychological, social, and ethical constructs (for example, guiding beliefs, value systems, norms, rules, and expectations) are often markedly different from those of civilian society. We do not know enough about how this legacy impacts the dying process in veterans and what the health services implications are, including in the context of general practice.

VETERANS' HEALTH AND END-OF-LIFE CARE IN GP PRACTICES — WORLDS APART?

There is a growing number of resources aiming to support GP practices in looking after their military veteran patients. Examples include the Royal College of General Practitioners' (RCGP) 'veteran-friendly GP practices' initiative,¹ the Veterans' Healthcare Toolkit, the Military Veterans e-learning course, and the Veterans Health Days of Health Education England. The provision of EoLC, in turn, apart from being a traditional role for GPs, has had its profile raised significantly via the Quality Improvement domain introduced in the 2019 GP contract. In Year 1 of the contract (2019/2020), practices could achieve 37

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points by engaging in continuous quality improvement of their EoLC services.² Yet the intersection between the two types of population — veterans at the end of life or, more broadly, veterans with palliative, end-of-life, and bereavement care needs — has not received any attention in the UK. This concerns all care settings and all relevant sectors — statutory health and social care, the military charities sector, and the health charities (including palliative, cancer, and bereavement care ones). Importantly, to our knowledge, there is no UK study on palliative, end-of-life, or bereavement care in veterans.

General practice does not appear to be an exception to this general tendency. Despite roughly coterminous high-profile initiatives in veterans' health and in EoLC, there seems to be no interest in the intersection of the two.

VETERANS AS PRACTICE PATIENTS

In the UK, a military veteran is anyone who has served for at least 1 day in Her Majesty's Armed Forces (Regular or Reserve) and those Merchant Mariners who have seen duty on legally defined military operations.³ The proportion of the UK veteran population in old age is sizeable: 60% of UK veterans are over the age of 65¹ and >50% are 75 or over.⁴ Definitive estimates of the number of veterans are difficult to reach, with figures varying between 2.4 million¹ and 2.8 million⁵ (the second estimate includes veterans residing in Northern Ireland, but this cannot explain the difference. Such veterans are believed to be approximately 2% of UK veterans⁶). Of these, between 90 000 and

98 000 are expected to die each year for the next decade (estimates based on data from Ministry of Defence report).⁶ No data are available on the number of veterans who may have palliative and EoLC needs. As with most patients, the aim will be to meet these needs through palliative and EoLC that is primarily community based and involves general practice.

A 2013 study on GPs' knowledge of veterans' health issues and the support GPs access and need in that respect⁷ struggled with a low response rate: of the 10 611 GPs in England contacted with a request to fill in an electronic questionnaire, only 303 responded.⁷ Such a low response rate may reflect low interest in veterans' health or low perceived relevance of the latter to the day-to-day work in general practice. But it may also signal suboptimal identification of patients with a military background. Only 7.9% ($n = 22$) of responders indicated that they used the veterans Read code on their clinical IT system.⁷ In light of such findings, the veteran-friendly accreditation of GP practices now requires that the records of military veteran patients be annotated accordingly.¹

IN ILLNESS AND IN DEATH — ARE VETERANS DIFFERENT?

Military veterans have been shown to have unique health and social care needs and patterns of help seeking in a range of fields (for example, mental health;⁸ alcohol abuse;⁹ limb loss;^{10,11} social isolation and loneliness, especially in older age;¹² and maintaining independence and receiving support at home¹¹). They have been found to experience 'distinctive and unique' difficulties⁹ in managing health conditions and behaviours and in seeking help, in ways that 'subtly differentiate' them from the wider civilian population⁹ or make them 'unique in various ways'.¹¹ A small number of veterans also have 'complex and enduring physical, neurological and mental

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health conditions resulting from injury that is attributable to Service’, which has given rise to work on ‘integrated personal commissioning for veterans’ (IPC4V).¹³

Veterans may be using palliative and EoLC services less than the general population. Servicemen and -women may become accustomed to high levels of pain and suffering. In contrast, being pain free is integral to the notion of a good death in the general population. One systematic review found that 90% of bereaved and pre-bereaved relatives and 83% of healthcare professionals rated freedom from pain as key to a good death.¹⁴ Some veterans have also dealt with significant trauma around facing, witnessing, and/or causing death and dying, possibly aided by trauma risk management programmes informed by psychological research (which are increasingly used in the military); formal sources of support (for example, the services of Combat Stress, Forces in Mind Trust, or the NHS Veterans’ Mental Health Transition, Intervention and Liaison (TIL) Service); informal sources of support, as provided by family and friends; and/or their own reflections and search for meaning. Overall, veterans may be well equipped to manage close encounters with pain, suffering, and death without seeking professional input. However, they may also be reluctant to seek help for avoidable suffering in terminal illness and/or at the end of life, even if they may be more receptive to such care than most people, as many of them can talk openly about death and dying.

A further aspect of the presence of pain for military veterans that may distinguish them from the majority of the general population is that older pain, of the type of ‘total pain’ familiar from palliative and EoLC (understood as the simultaneous experience of physical, psychological, social, spiritual, and practical struggles), may resurface in later life. For instance, research on dementia in older veterans reveals that some may lose their capacity for ‘stiff upper lip censoring’ of traumatic memories, resulting in their

resurfacing.¹⁵ Ageing veterans may also be more susceptible to Late-Onset Stress Symptomatology (LOSS), as triggered by later-life stresses associated with awareness of one’s mortality or changes to routines that previously helped to maintain functional ability.¹⁶ It is plausible that veterans may have needs and preferences for palliative and EoLC that are different from those of the general population. It is also conceivable that they may underutilise associated services.

PALLIATIVE, END-OF-LIFE, AND BEREAVEMENT CARE RESEARCH ON (NON-UK) VETERANS

Scarce research, primarily from the US, tentatively confirms such expectations. For instance, Wachterman *et al*¹⁷ found that veterans were more likely to receive hospice care at home, but less likely to be visited by healthcare providers, potentially reflecting a sense of pride in asking for help or lesser self-perceived need for assistance. Similarly, Duffy *et al*¹⁸ found that veterans felt more strongly than non-veterans that their doctors should be frank and open with them and less strongly about remembering personal accomplishments, being listened to, being with friends, or being comfortable with their nurse.

Bereavement among veterans is also underexplored. Military deaths are often experienced in the context of ‘unique bonds between service members’, persistent and extreme levels of stress, multiple losses, younger age, separation from loved ones, and may require the handling of bodily

remains.^{19,20} Grief is typically addressed quickly by a unit memorial service, whose implicit message is that the grieving process is ending and the mission continues.²¹ Military culture and the warrior ethos, with the values they ascribe to sacrifice, heroism, and stoicism, may shape both short- and long-term grief responses.²⁰ The death of a comrade or comrades may also be one of many concomitant experiences of trauma and loss. Those grieving may have experienced devastating wounds and injuries themselves, resulting in permanent loss of physical and mental functions.²⁰ Survivors can then be suddenly ‘ripped’ from the familiar environment of military life and stripped of their identities, ‘*thrust into a civilian world that they may not have experienced recently and left to grieve alone*’.²²

INTERSECTION WITH TRAUMA AND MENTAL HEALTH RESEARCH

A further largely overlooked issue of crucial importance for the delivery of palliative and EoLC services for veterans is the intersection between a history of trauma, including post-traumatic stress disorder (PTSD), and approaches to providing palliative and EoLC. This is a generic research gap. The overall incidence of PTSD in the UK Armed Forces is only slightly elevated in comparison with that in the general population,²³ despite the strong relationship between PTSD and military history in the social discourse, including among GPs.⁷ However, there are substrata within the Armed Forces where the prevalence of PTSD is dramatically higher, for example, 17% among veterans whose last deployment was in a combat role.²³ It is also arguable that such figures may underestimate a significant problem because of the stigma associated with it. A recent review of assessment and treatment for PTSD at the end of life²⁴ identified a dearth of research, with veterans among the few populations where trauma survivors have been followed longitudinally. No diagnostic instrument for PTSD has been

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Box 1. Key messages

- Between 90 000 and 98 000 veterans are expected to die each year for the next decade.
- The NHS and the Royal College of General Practitioners are starting to differentiate between veterans and non-veterans with regard to healthcare needs but palliative, end-of-life, and bereavement care needs have received no attention.
- Military veterans are likely to have encountered death, pain, and suffering like few other groups in society, potentially resulting in group-specific attitudes and behaviours in dealing with life-limiting illnesses and/or approaching the end of life.
- Research on palliative, end-of-life, and bereavement care in UK military veterans is urgently needed.
- The role of UK general practice in caring for veterans with palliative, end-of-life, and bereavement care needs is unclear, not least because we do not know whether those needs are largely generic or group specific.

validated for use at the end of life.²⁴ PTSD is also unlikely to be a presenting complaint in such contexts. For instance, older veterans have been shown to discuss traumatic wartime experiences predominantly with former comrades,¹⁵ while presenting for health care with somatic symptoms.²⁴ Current distress or behavioural symptoms (such as agitation or irritability) may not be easily identified as related to past trauma,²⁴ including by GPs and other members of the primary care team. Psychological distress may also be normalised in the dying process. Assessment is further complicated by comorbid dementia, delirium, and pain. Yet, as a form of significant psychological distress, PTSD can obstruct making treatment decisions, obtaining closure with family and friends, tolerating pain, and engaging in social relationships. Many patients with PTSD also have strained social relationships and thus reduced social and caregiver support, with the latter often a crucial factor for a good death.²⁴ These are complex presentations and circumstances, with GPs and members of the broader practice team having no easy access to sensitising information to support the identification of the core issues and no sharply targeted specialist services to refer to.

PROPOSALS FOR THE WAY FORWARD

The UK government, the NHS, and the RCGP are starting to differentiate between veterans and non-veterans with regard to healthcare needs, including through the Armed Forces Covenant, the NHS Long Term Plan, and the veteran-friendly GP practices programme, but palliative, end-of-life, and bereavement care needs are lost to the discussion. This is despite a strong policy commitment to personalising palliative and EoLC, and organising it around a patient's wishes, preferences, and values, recorded and shared through individualised care plans. At a time when attention to

the way we die and how accompanied or abandoned dying patients may feel has increased significantly because of the COVID-19 pandemic, it is important that we do not forget an 'army' of approximately 100 000 veterans dying in the UK per year for the next decade. Unfortunately, we know close to nothing about their palliative and EoLC needs and appropriate ways to address them (see Box 2 for generic resources on veterans' health). Relevant research is urgently needed, with some priorities being:

- inductive, qualitative research that elicits the perspectives, experiences, and meaning making of veterans themselves, which takes extra care not to induce expectations of participants presenting a 'warrior persona';

- the intersection between palliative, end-of-life, and bereavement care, on the one hand, and mental health, on the other, particularly in relation to psychological trauma;
- the specific opportunities and challenges arising in different contexts of service delivery — general practice; veterans' charities; specialist palliative and EoLC services; care homes (including veterans' ones, such as the Royal Star and Garter Homes); hospices, for example. The perceptions of staff as to 'whose job' it is to care for veterans approaching the end of life also need exploration;
- robust evaluations of pilot programmes; and
- emphasis on diversity in user involvement, due to the breadth of roles, experiences, and service-related health conditions within the armed forces.

While expansion and sustainable funding for veterans' health programmes in general practice, such as the RCGP veteran-friendly GP practices initiative, is required, it is unclear if general practice should lead in the provision of palliative and EoLC for veterans. It is too open a question of how 'general' or 'specific' the needs of this patient group are.

CONCLUSIONS

Veterans may seek help from members of

Box 2. Generic resources on veterans' health

- Royal College of General Practitioners veteran friendly GP practices programme:
<https://www.rcgp.org.uk/clinical-and-research/resources/a-to-z-clinical-resources/veteran-friendly-gp-practices.aspx>
- Contact Armed Forces, webpages for healthcare professionals:
<https://www.contactarmedforces.co.uk/we-can-help/healthcare-professionals>
'Contact' is a group of military charities (including the Royal British Legion, Help for Heroes, Combat Stress, for example) *who have come together with the NHS, the MOD and Royal College of Psychiatrists to ensure that the best mental health support possible is available to those who have served in the British Armed Forces and their families*.
- Veterans' Gateway:
<https://www.veteransgateway.org.uk>
'We put veterans and their families in touch with the organisations best placed to help with the advice and support they need.'
- Veterans & Families Research Hub:
<https://www.vfrhub.com>
- Veteran Aware NHS Trusts:
<https://www.england.nhs.uk/personalisedcare/upc/ipc-for-veterans/veteran-aware-nhs-trusts>

their general practice team — or, indeed, avoid doing so — enacting beliefs and expectations of health care, suffering, and themselves strongly influenced by their military history. Whatever our politics and stance on war, we have a duty of care to them. Performing it adequately demands increased awareness, sensitivity, and non-trivial adaptations, all the more in the complex context of death and dying.

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