Experiences and Support Needs of Veterans Living with Dementia

By Dr Lydia Morris, Prof Anthea Innes, Ms Helen Morley,
Dr Ana Churchman

CONTENTS

ACKNOWLEDGEMENTS 2

FOREWORD 3

ABBREVIATIONS 4

EXECUTIVE SUMMARY 5

BACKGROUND 12

Project aims 15

Project design 16

Key stakeholders 20

Service and ex-Service personnel and their families' involvement 21

PHASE 1 22

PHASE 2 31

PHASE 3 39

KEY RECOMMENDATIONS 43

DISSEMINATION 47

References 48

ACKNOWLEDGEMENTS

We extend our thanks to members of our Research Advisory Group and the organisations and individuals who helped us identify potential participants. Thank you also to the Forces in Mind Trust for funding and supporting this work throughout. Finally, we extend our gratitude and thanks to all our study participants for their invaluable sharing of their experiences at interviews and also during the workshops

FOREWORD

Almost one million people in the UK have dementia, a condition that can have a significant impact on individuals and their families including changes in behaviours, difficulties performing daily tasks and modified family dynamics. Little is currently known about the experiences of ex-Service personnel living with dementia in the community and, as a result, their views are not being heard in the design and delivery of services, and it is not known whether current services are meeting their needs. We were therefore pleased to fund this research to examine the experiences of ex-Service personnel and their families as they navigate dementia diagnosis and support.

The research suggests that ex-Service personnel are stuck in the middle of two systems of support - one focused on generic dementia care and the other focused on veteran-specific support. Findings highlighted a lack of awareness, shared expertise and communication between the two systems, making it difficult for ex-Service personnel and their families to have any unique needs understood by service providers. This is in addition to the challenges experienced by individuals with dementia in the wider civilian population such as issues accessing diagnostic services, in some cases caused by the stigma associated with dementia, and a lack of awareness of post-diagnosis support.

Whilst this study may be small, the in-depth interviews provide valuable insights on the lived experience of ex-Service personnel living with dementia and their families and care givers. It is a crucial first step in helping to ensure that they feel understood, respected and have access to appropriate support whilst continuing to live in their own homes. It also offers examples of good practice that should be built upon and properly resourced; these are often provided at a local level through community-based services that provide individualised and holistic support.

I hope that policymakers, healthcare staff and commissioners, and military support services consider the report’s findings and come together to create a system that is both veteran and dementia aware, ultimately enabling ex-Service personnel and their families to live well with dementia in the community.

Michelle Alston, Chief Executive, Forces in Mind Trust

ABBREVIATIONS

VLWD – Veteran Living with Dementia

HCP – Healthcare Professional

SP – Service Provider

CP – Care Partner

RAG – Research Advisory Group

FiMT – Forces in Mind Trust

EXECUTIVE SUMMARY

Background: Despite an increased focus on dementia nationally and internationally little evidence exists on veteran experiences of dementia. Accounts of supporting veterans with dementia living in the community in the UK are particularly rare. Research about experiences of veterans with dementia in Taiwan and the US demonstrates the need for improved services and support to enable veterans to live well with dementia. In the UK there is a paucity of research about veterans' experiences of living with dementia and the support they receive or would like to receive; a gap this study aims to help address.

This study is the first UK based qualitative work that focuses on the everyday lived experiences of veterans with dementia who live in the community. Such experiences include veterans' perceptions of the diagnostic process, of accessing support, and of the impact of having a diagnosis of dementia while also being a military veteran. We also aimed to explore the links between previous experiences in the Armed Forces and the dementia diagnosis as perceived by those with the condition. Our findings offer an important first step in developing an evidence base that can help to inform policy and practice, thereby ensuring that effective and accessible support is available to both veterans with dementia living in the community, and also to their family members.

Risk factors of developing dementia rather than experiences of living with dementia has been the focus of most dementia veteran research to date. In the US and UK specifically, the primary research focus around dementia in veteran populations has been understanding risk factors for developing the condition and whether veterans are at higher risk of developing dementia. The findings from UK studies thus far differ to a degree from the findings from US studies, in that sustained US research (Kornblith et al., 2020; Rafferty et al., 2018; Snyder, Carare, DeKosky et al., 2018; Weiner et al., 2013) reports an increased prevalence for dementia in veterans due to factors such as traumatic brain injury and post traumatic stress, whereas a large UK research study found a lower risk of dementia for veterans (compared to non-veterans) in community-based samples (Greig et al., 2021); and a more recent large comparative study (Scottish veterans vs. non-veterans) found no difference in risk of dementia between the two groups overall, but found a strong association of developing dementia among those with a history of mood disorder (greater so in veterans) and those with post-traumatic stress disorder (PTSD) (Bergman et al., 2023). Additionally, a smaller UK case-control study (N = 121) concerning those still serving found no evidence for an association between psychological ill health and dementia (Greenberg et al., 2020). Given the different results in different studies, additional quantitative data is required.

Whatever the predisposing and risk factors, evidence suggests veterans living with dementia face challenges. For example, a thematic scoping review of 36-studies by Ritchie and colleagues (2019) found that the post traumatic stress that some veterans with dementia experience, poses distinct support needs and care challenges. In addition, the focus of this study is on the experiences of veterans living with dementia in the community; even if UK veterans are not at increased risk of dementia compared to non-veterans, their experience of living with dementia and accessing and navigating services may still be different. For example, as noted above, the large comparative study of Scottish veterans by Bergman and colleagues (2023) found the association of mood disorder with dementia was stronger in veterans compared to non-veterans and recommendations included that healthcare providers should carefully assess the cognitive status of older veterans presenting with depressive illness to identify early dementia.

What we did:

1. Conducted the first UK based research focussing on the everyday lived experiences of veterans with dementia who live in the community.

2. Explored the links between previous experiences in the Armed Forces and the dementia diagnosis as perceived by those with the condition within the study.

3. Provided an initial basis of evidence on which to build, and from which to inform policy and practice to ensure effective support is available to veterans with dementia living in the community and their family members who provide support and care.

This research project had three phases:

Phase 1: Interviews with 15 service providers to explore their experiences of providing support to veterans with dementia living in the community from their perspectives to identify challenges as well as good practice. Over a period of seven months, the project team contacted 85 service providers in North-West England (including national providers who operated in the area); of these, one offered a specialist service for veterans living with dementia in the community, with another having offered such a specialist service previously. Of the 15 interviewed, three offered dementia specific services, nine offered veteran specific services, one offered specific services for veterans living with dementia, and two were focused on Older Adults (including those with dementia). Five of the 15 were supporting at least one veteran living with dementia at the time of interview, and one had done so in the recent past.

Phase 2: Eleven in-depth interviews, using a semi-structured template over a period of four months, with veterans with a diagnosis of dementia, and with their care partners (six veterans; five care partners). Phase 2 fieldwork area was expanded to the whole of England following recruitment challenges. Three veterans also completed a diary. The remaining veterans did not complete a diary primarily due to changes and deterioration with their dementia symptoms.

Phase 3: Two policy and practice workshops were held as a mechanism to share the study findings with interested stakeholders and to help prioritise the recommendations for policy and practice to be considered beyond the project.

Findings: The research found current gaps in understanding about the experiences and support needs of veterans diagnosed with dementia who continue to live in their own homes in the community. Our findings suggest that these veterans may be under-served by current support and may be having particular difficulty accessing and utilising the support and services available.

In terms of access to services, from the service provider perspective, provision of sustainable services for veterans living with dementia often relied on community-based support groups and related initiatives. The initiatives were often short-lived due to short term funding, primarily from charities or benefactors. Ongoing specialist support for veterans living with dementia in the community was limited, with the Royal British Legion providing an ongoing service (via Admiral Nurses) and some veteran specific residential and care homes offering community activities (although a lot of these ceased during the COVID-19 pandemic and were in the early stages of being revived at the time of this study).

Participants reported issues in navigating the different service options available, with specific comments that services were not always coordinated or 'joined-up' (veterans and care partners voiced particular frustration about the 'fragmented' nature of 5services). Specific challenges experienced by veterans related to them and their care partners not being informed of the service options that were available. In addition, services were not always well advertised and gatekeepers to services could also have a lack of knowledge about the services available to veterans. Although this is not necessarily an experience limited to veterans, what could be specific to veterans are particular challenges and barriers experienced in accessing services due to the intersectionality of their identity as both a veteran and someone living with dementia. These challenges to service access could be partly due to the impact of the military culture of stoicism and self-reliance (Heward et al., 2024) or to perceived stigma (Randles & Finnegan, 2022) [note that the impact, and potential disadvantage to service access, of intersecting identities is already well established within the context of other potentially underserved communities, such as cultural and ethnic minorities; for example, Dodd et al., 2022; Duran-Kiraç et al., 2022]. Indeed, our research found that several veterans (and their care partners) discussed issues that suggested the very stigma of having a dementia diagnosis meant they did not wish to access dementia services, a stigma likely to be felt all the more strongly if the military culture mentioned was still impacting their behaviour. Concerning perceived links between previous experiences in the Armed Forces and dementia diagnosis, the veterans within our study did not perceive any such links.

Service providers reported that veteran identity and pride in their individual service histories often featured as important. At interview, veteran and care partner participants similarly stated how much they appreciated support services that took this into account; for example, opportunities for veterans to meet with other veterans in social or breakfast clubs. Both veterans and service providers indicated that in some cases, veterans living with dementia were much more likely to attend services and support interventions if they involved other veterans. Generally participants identified as helpful: a range of social groups, flexible and individualised (person centred) provision, signposting and collaboration and support for service providers.

Challenges encountered and limitations: We encountered a variety of challenges when conducting this research. First there was a legacy of the COVID 19 pandemic where some services no longer existed, staff had moved on during the period between applying for and beginning the research leading to the research team needing to establish new community links to assist with recruitment; also sadly many of the veterans living with dementia that service providers had been aware of at the application stage had either died or moved on from community based care into residential care. We adapted to the challenges by seeking ethical approval and then extending our study catchment area from the North West of England to the whole of England, and also to include veterans who had recently moved into a care home. These extended criteria helped a little with the identification and recruitment challenges but did not resolve our challenge in reaching our target sample size. The other challenge we faced was 'false' participants, by this we mean participants who claimed they were veterans but who would not turn on their cameras or who did not know what a veteran was, again we adapted to this challenge by introducing an additional screening protocol (after receiving ethical approval to do so) and this enabled us to screen out such participants more quickly. However, recruitment challenges undoubtedly impacted on the research process.

There are limitations to this project and these impact on the generalisability of the conclusions and specific recommendations that can be drawn. The key limitation is that the sample size is relatively small for the phase involving veterans living with dementia and their care partners. As with all exploratory qualitative research, this study aimed to identify themes rather than quantify scale. Reflexive thematic analysis, the qualitative method selected for the veteran analysis, is well suited to capturing the depth and potential complexity of participant experience. Given that the sample of veterans living with dementia and care partners is a specific one, and that the study aim was not to provide a detailed cross case analysis but rather to explore and identify potential areas of interest for future investigation, the informational power[1] of this study was adequate.

Key recommendations from this work are:

1. IDENTIFY VETERANS – this could be achieved by increased encouragement for General Practitioners, healthcare workers and Memory Assessment Teams to ask about military service history – particularly at appropriate dementia diagnostic screening points within health and social care. This could be achieved by a greater number of GP practices signing up for the Veteran friendly GP Scheme. In addition, it would be useful if Memory Assessment Teams (who generally conduct dementia diagnoses) asked about veteran status so that they can signpost to appropriate support. Doing so would enable veterans to be pointed to services that maybe available, such as breakfast clubs or holidays, that cater to the unique identities of veterans.

2. PROMOTE JOINED-UP WORKING – this could be achieved by creating opportunities for service providers and those using services to come together and proactively consider what military-informed service support, and pathways to access that, are required to help reduce any real or perceived gaps in support and ensure more cohesive, joined-up approaches. There are different ways that this can be achieved but a key approach relates to local services being aware of what is on offer and signposting appropriately. It is imperative that there is dialogue and knowledge across the general dementia support services and veteran specific support services as a starting point if approaches are to be found that will help ensure no veteran living with dementia falls between the ‘cracks’ of fragmented provision.

3. DEVELOP DEMENTIA SPECIFIC SERVICES FOR VETERANS. Some participants expressed a preference for veteran-specific support, reflecting the continued importance they attributed to their identification as part of the veteran community. A first step to achieving this is by providing dementia training to the staff and volunteers working in veterans’ services; and providing veteran-informed training and greater awareness of the veteran-specific support available in the local area to generic dementia services

---

[1] Information power is a concept that helps determine appropriate sample size for a study within some qualitative research.

(ensuring in the latter case they know (how) to signpost to military specific support where useful).

4. PROVISION OF SUPPORT FOR FAMILY MEMBERS AND CARE PARTNERS. Enabling the veteran living with dementia to remain in the community and at home often requires the support of family members and care partners. Just as veteran dementia services need to be tailored to recognise both the dementia specific and veteran identity challenges that present unique support requirements, the family members and care partners of veterans may require support for challenges that symptoms of dementia poses and also the specific need to be able to support a veteran with dementia who may for example relive service experiences. Therefore, support services, for example, support groups for family members need to be able to acknowledge and provide expertise in relation to particular challenges that may arise in relation to memories of service and how to recognise and provide strategies to support reliving traumatic memories.

5. FURTHER RESEARCH. Further research would help further inform where specific interventions and services for veterans living with dementia need to be developed and offered, and/or (current) policies developed to help ensure this vulnerable cohort is fully supported and at no disadvantage. For example, comparative quantitative work that looks at service use for both veterans living with dementia and the general population diagnosed with dementia. However, quantitative research is not well placed to capture the complexity of identity and how this can impact service use so additional qualitative research should be conducted with a specific focus on this; directly recruiting from NHS services should be factored into the timeline and funding. There is a pressing need to understand where (if at all) the experiences reported in this study differ or not to those of civilians with dementia to be able to argue for changes in practice in keeping with the Armed Forces Covenant (Ministry of Defence, 2022). It could also to useful to compare the experience of military veterans, with for example the experiences of blue-light service veterans who may experience service-related issues leading to PTSD and reliving of such experiences when dementia emerges.

BACKGROUND

Despite an increased focus on dementia nationally and internationally there is limited research regarding veteran experiences of dementia. Accounts of supporting veterans with dementia living in the community in the UK are particularly rare (Hutchinson 2018). Mileski et al (2017) systematic review of 14 studies aimed to identify: opportunities available to increase public awareness on the subject; areas of improvement in the level of care and quality of life for US veterans; and whether adequate resources are available for veterans with dementia and their caregivers. They concluded that: '*Veterans are hindered from receiving help with their dementia concerns due to most veterans' dependence on the Veterans Affairs (VA) for health services, a lack of education about possible treatments and programs, and a lack of services in rural areas'* (page e1904). Issues raised, such as an unequal distribution of, and sometimes lack of, services has been reported in the generic dementia literature. Within Taiwan and the US, interventions have been developed and evaluated to support veterans living with dementia to improve their health and social care service experience. Research about experiences of veterans with dementia in Taiwan (Chen et al 2017) and the USA (Ching-Teng 2020, Bass et al 2015, Gitlin 2013, Zhu 2009) demonstrates the need for improved services and support to enable veterans to live well with dementia. These studies include quantitative studies of service and interventions aimed to support veterans living with dementia and improve their care, such as coordinated care approaches to reduce hospital admissions and a longitudinal study investigating service use in the US that concluded additional coordination between services was required. In the UK, there is a paucity of published or publicly available research about veterans' experiences of living with dementia and the support they receive or would like to receive; a gap this study aimed to address.

Risk factors of developing dementia rather than experiences of living with dementia has been the focus of most dementia veteran research to date. In the US and UK specifically, the primary research focus around dementia in veteran populations has been understanding risk factors for developing the condition. The findings from UK studies thus far differ from the findings from US studies, in that US research (Weiner et al 2013, Snyder et al 2018, Rafferty et al 2018, Kornblith et al 2020) consistently reports an increased prevalence for dementia in veterans due to factors such as traumatic brain injury and post-traumatic stress, whereas one large UK research study (Greig et al 2021) found a lower risk of dementia for veterans (compared to non-veterans) in community-based samples. A smaller UK case-control study (N = 121) found no evidence for an association between psychological ill health in service and dementia (Greenberg et al 2021). A large comparative study (Bergman et al 2023) of Scottish Veterans (78 000 veterans; 253 000 people with no record of service) found that a history of mood (depressive) disorder was a major risk factor for the subsequent development of dementia in both veterans and non-veterans, but the risk of developing dementia was disproportionately increased for veterans (where a mood disorder was also diagnosed). PTSD was associated with a higher risk of dementia in both veterans and non-veterans (Bergman et al 2023). It is interesting that thus far results from UK studies into risk factors are different from the majority of US based studies, in that they do not report an increased prevalence for dementia in veterans vs non-veterans. However, given the greater number of larger studies in the US that focus on specific risk factors for dementia within military veterans, the US literature provides an additional useful context.

Whatever the predisposing and risk factors, evidence suggests veterans living with dementia face particular challenges. For example, Ritchie et al's (2019) thematic scoping review of 36-studies indicates that the post-traumatic stress disorder (PTSD) that can be evident in veterans with dementia, poses distinct support needs and care challenges. Research literature generally indicates that veterans who have been deployed are at high risk of PTSD (Xue et al 2015; Oster et al 2017) and rates of PTSD within UK military personnel are approximately 6%, which is slightly higher than seen in the general population (~4%) (Stevelink et al 2018). The rates of PTSD are generally higher in veterans than in the general population; for example, Sharp and colleagues (2024) found an 11% risk of probable PTSD in ex-serving regulars, 18% in those who had deployed in a combat role, and only 7% in those still serving. A US based study (n = 181 093) found that veterans with a PTSD diagnosis had a two times higher risk of dementia compared to veterans without PTSD over a 7-year cumulative period (Yaffe et al 2010). Veterans who develop dementia may have specific military experiences that they relive; this could include experiences previously coped with and adjusted to (Bergman et al 2023, Ritchie et al 2019) but that later re-emerge during their transition to living with dementia. This is important because of the memory changes that occur in most types of dementia, whereby early life experiences (eg teens, 20s and 30s) become more vivid and past experiences form a greater part of people with dementia's current reality.

Much research about veterans focuses on earlier stages of transition to civilian life; older veterans, for whom service would have been a considerable number of years (likely decades) earlier, are a cohort that is less well researched, with research that focuses on their experiences of dementia being largely absent. It is against this backdrop that we wished to examine the lived experiences and self-identified support needs of veterans with dementia in the UK, as it could have important implications for policy and practice in the short and long term when it comes to ensuring veterans who have dementia - and are still living in their own homes - are supported in a way that enables them to live well with dementia.

The main partners and stakeholders of this study are veterans living with dementia, their family members and organisations (veteran and general) who provide support and care.

PROJECT AIMS

This study aimed to address the current gap in knowledge and understanding about the experiences and support needs of veterans diagnosed with dementia who continue to live in their own homes in the community.

The aims were to:

i. Conduct the first UK based empirical work focussing on the everyday lived experiences of veterans with dementia who live in the community.
ii. Explore the links between previous experiences in the Armed Forces and the dementia diagnosis *as perceived by* those with the condition.
iii. Provide an initial basis to develop an evidence base able to inform policy and practice to ensure that effective support is available to veterans living with dementia in the community and their family members who provide support and care.

Our primary research questions were:

1. What are the self-reported everyday experiences of living with dementia for veterans who continue to live in their own homes?
2. What are the reported dementia support needs of veterans and their family members?
3. What are the possible policy and practice implications for supporting veterans with dementia?

PROJECT DESIGN

DESIGN: This three-phase qualitative study was designed to elicit the experiences of veterans living with dementia who continue to live in their own homes.

Phase 1: **Interviews with service providers (n=15)** to ascertain the issues of providing support to veterans with dementia living in the community from their perspective. The project team contacted 85 veteran and dementia service providers and organisations in the North West (including national providers who operated in the North West); of these one offered a specialist service for veterans living with dementia living in the community and one had offered one in the past. Of those interviewed, three offered dementia specific services, nine offered veteran specific services, one offered specific services for veterans living with dementia, two were focused on Older Adults (including those with dementia). Five were supporting at least one veteran living with dementia at the time of interview, one had done so in the recent past.

Phase 2: **In-depth interviews with veterans (n=6) with a diagnosis of dementia and their care partners (n=5)**. Veterans living with dementia were accompanied, should they wish, by their family member(s); if they did not wish to be accompanied, then their family member(s) was interviewed separately to explore their own support needs (and their perceptions of what the veteran they were caring for needed). If both a veteran living with dementia and care partner were interviewed then questions were directed at both parties. All veterans had capacity to consent to participate (the research team followed established and ethically approved guidelines for process consent (Dewing 2007), in line with the Mental Capacity Act).

Veterans were asked whether they would be willing to complete an optional diary; three participants completed one. We anticipated more participants would complete diaries, but several were unable to due to memory difficulties (ie remembering to complete the diary), issues with holding a pen/ pencil, or simply did not want to complete a diary. We did not exclude participants on this basis.

Phase 3: **Two policy and practice workshops** with a range of stakeholders (n= 44) designed to share the study findings and to shape the next steps in the project.

Recruitment: Eighty-five service providers in North West England (including national providers who operated in the North West) were contacted. We recruited through RBL, including the specialist Admiral Nurse Team and specific veteran dementia care homes; in addition to general veterans' organisations such as Veterans' Gateway and the Royal Air Forces Association. We contacted other organisations, including specialist care homes, but were generally advised that day and community support had not yet re-commenced post-COVID.

A purposive sample of veterans living with dementia and their care partners in England was recruited via the National Register Join Dementia Research database https://www.joindementiaresearch.nihr.ac.uk/), the DEEP network [ie a National database of organisations that provide support (including peer support groups) to people living with dementia in their own homes], contacts through Phase 1 service provider interviews, and the Association of Service Drop-in Centres directory. Our networks of voluntary sector dementia and veteran organisations also provided opportunities for recruitment support. We contacted and recruited through various contacts at dementia services, including Age UK and Alzheimer's Society; and through several sports organisations that offer veteran specific support. Regular contact was made with service providers and key stakeholders once they had agreed to support study recruitment, and with individuals who had expressed an interest in participating. This contact included sending advertisements and email updates (which were also circulated around relevant veteran and dementia specific databases).

Phase 1 involved contacting a range of service providers as detailed above.

Phase 2 entailed recruiting veterans living with dementia and care partners.

Phase 3: Phase 1 and 2 participants, and targeted service providers, policy makers, veterans living with dementia and their care partners, were invited to two workshops.

This multi-pronged approach aimed to maximise the success of the participant recruitment phase.

INCLUSION CRITERIA FOR VETERANS

- Self-identifying as a veteran living with a diagnosis of dementia was the primary inclusion criterion. Veterans who served in a range of capacities (including active service as a Health and Social Care Professional within the military) were also included.
- The ability to give consent was assumed (in line with Mental Capacity Act). If there were concerns about mental capacity to the extent that consent could not be given, then only the inclusion of the care partner was considered. Process consent (Dewing 2008) was followed. In line with the Mental Capacity Act, capacity was assessed in relation to the specific decision to take part in the study in terms of whether the veteran living with dementia could: understand the information relevant to the decision, retain that information for long enough to make the decision, use or weigh up that information as part of the process of making the decision, and communicate their decision. Appropriate steps were taken to support the veteran's decision-making process if beneficial (in line with the Mental Capacity Act).
- The ability to communicate verbally.

METHODS

Focused interviews: Hearing the voice and experiences of people living with dementia is essential in research (Alsawy et al 2020, Bowker et al 2020) and key to influencing policy and practice (Pickett et al 2018). Interviews were conducted face-to-face or, if necessary, via telephone or online platforms. All interviews (phases 1 and 2) were digitally recorded and either fully transcribed or partially transcribed at the time of interview, with the participant's consent. Demographic data was recorded with consent. See Appendix A and B for the service provider interview schedule and veteran interview schedule, respectively. Appendix C contains adapted questions for care partners.

Phase 1 Sample size: Interviews were conducted until saturation of themes occurred (Guest et al 2006). Saturation is defined in terms of "the point in data collection and analysis when new information produces little or no change to the codebook" (Guest et al, 2006, p. 65).

Phase 2 Sample size: Within the veteran and care partner analysis, saturation did not apply (as reflexive thematic analysis was used) and instead informational power informs the sample size. Referring to informational power (Malterud et al, 2016), the sample of veterans living with dementia and care partners is a specific one and the study aim was not to provide a detailed cross case analysis but rather to identify potential of interest for future investigation. On the basis of the guidance of Malterud et al (2016) and Braun and Clarke (2022), it is indicated that adequate informational power was achieved and rich data was provided.

Phase 1 Data analysis: Using Miles et al (2014) three phases of:

i. <u>data condensing</u> (reviewing participants' experiences, coding sections of the narratives into initial themes, then generating categories to group these themes into nodes);
ii. <u>data display</u> (differences between the themes from veterans, families and service providers); and
iii. <u>drawing conclusions</u> (using final nodes, conclusions are drawn and verified with the narratives and relevant literature).

One researcher (AC) reviewed all the transcripts and developed a codebook which was reviewed by two other researchers (AI and LM). Following on from multiple discussions, refinements were made to the initial codes.

Phase 2 Data analysis: Reflexive Thematic Analysis (TA) was used. This is a well-established qualitative analysis method and is particularly suited for under-researched topics that focus on individual experiences (as well as themes across groups). Reflexive TA also offers a clear process for researchers to consider and reflect on how their experiences, biases and perspectives directly affect the interpretive process. This is particularly important for research with under-served groups and those with intersecting and potentially complex identities; for example, having both a veteran identity as well as the identity of a person living with dementia. Care partner identities can also be complex: carers do not always identify with the carer role for reasons such as identifying solely or primarily with their pre-existing role as a spouse.

Computer data management software, NVIVO, was used to "Index, Search, and Theorize".

One researcher (HM) reviewed all the transcripts and developed initial codes which were reviewed by two other researchers (AI and LM). Following on from discussions, refinements were made to the initial codes. Themes were also reviewed and re-reviewed by the research team with reference to the data.

Reflexivity statement and rigour

The researchers reflected on the fact that they were all female, white British or European. Two members of the team had professional clinical experience and training in psychology. The majority of the research team had personal experiences of family members with dementia. Two team members had extensive experience of researching the lived experiences of people living with dementia and care partners (AI and LM). No member of the team had personal experience of serving in the Armed Forces. One team member (LM) had some professional experience of working clinically with veterans with mental health needs; LM has more prolonged and significant experience of working clinically with people living with dementia and care partners. The research team used structured methods to analyse interview transcripts collaboratively, reviewed and agreed the coding methods and thematic structure together, engaged in reflective discussions, and HM kept a reflective diary used as the basis of team discussions.

Ethical considerations: Ethics approval was obtained from the University of Manchester and McMaster University research ethics committee on 8th March 2023 with further amendments granted as the project progressed.

KEY STAKEHOLDERS

Veterans living with dementia and their families were the intended primary beneficiaries of this research. By sharing their experiences, lessons for future policy and service provision can be highlighted to those designing, commissioning and providing support and care.

Service providers (generic dementia, generic veteran and dementia/age specific veteran) were also intended to benefit via the sharing of practices across different organisations.

The overall project was designed to maximise learning and impact. Two invite-only policy and practice workshops aimed to share interim and final findings (respectively) from the research interviews with service providers and with veterans with dementia and their care partners; discuss and identify gaps in service provision and/or policy; learn from one another; propose veteran-focussed solutions, and inform study recommendations and information dissemination (Lourida et al 2017, Harrison et al 2020). Key stakeholders attending the workshops included a Public Affairs and Campaigns Officer for Royal British Legion (RBL) whose role included policy and campaigning, in addition the Lead Admiral Nurse for RBL; military service organisations (eg, Trafford Veterans); and dementia service providers (eg, Dementia UK and Age UK - both of whom have had active partnerships with Armed Forces Charities), as well as veterans with a dementia diagnosis and their care partners (the veterans living with dementia and care partners included those who completed a research interview and those who did not).

SERVICE AND EX-SERVICE PERSONNEL AND THEIR FAMILIES' INVOLVEMENT

An important aspect of this study is that the project itself was developed over time through lived experience discussions with veterans and their care partners, key messages from which were that not enough is understood about their specific experiences and support needs. To guide the planning, conduct and evaluation of the project, a **Research Advisory Group** (RAG) was established which included service, ex-service personnel and their families. This group met four times over 18-months. There were 14 members: four project team members; a Researcher and member of the Armed Forces community as co-Chair; one current and two ex-care partners for veterans living with dementia; one long-standing member of the Armed Forces community; three service providers, and a representative from The Royal British Legion with expertise in public affairs and campaigning. The membership changed slightly during the project as one service provider changed roles, and another joined. The RAG members were invited to both workshops (October 2023; April 2024). Veterans living with dementia and their families were key to phase 2 of this research (ie as participants). As key stakeholders in the project, participants from phase 1 were invited to participate in phase 3, the policy and practice workshops. The RAG directly contributed to the design and content of both the workshops.

PHASE 1

Participants and recruitment

The researchers approached over 85 service providers across the North West (NW) (Greater Manchester, Lancashire, Yorkshire, Merseyside) – including national providers who operated in the NW - to request an interview. Fifteen services agreed to speak about the services they offered. Of those interviewed, three offered dementia specific services, nine offered veteran specific services, one offered specific services for veterans living with dementia, and two were focused on Older Adults (including those with dementia). Five were supporting at least one veteran living with dementia at the time of interview, and one had done so in the recent past. All participants were white British, and interviews lasted between 25 and 52 minutes. The interviews were guided by a topic-guide and focussed on issues of providing support to veterans with dementia living in the community from the service provider perspective. The research explored not only what is currently provided by the service providers but the perceived challenges and opportunities, and perceived gaps in the support offered.

Recruitment challenges

Over 85 service providers (primarily community-based, third and charitable sector) were approached across the North West, with 15 agreeing to participate. One potential barrier was that most of the organisations we approached were either not directly set up to support veterans living with dementia, or were not clear if veterans were using their services - as such they felt they could not contribute. To help with this, members of the RAG supported recruitment by linking the research team to additional services and, in certain cases, with veterans directly.

Table 1: Phase one themes and sub-theme table

Theme	Sub-themes
Complexities of support	• individualised needs • logistics, access and cost • services not specifically designed for veterans living with dementia
What service providers are offering that is working well	• social and community groups • reacting to need and flexible provision • collaborating and signposting

Challenges in providing support	- how to support veterans in generic services - how to engage care partners - there can be similarities and differences in the support needs of veterans living with dementia compared to civilians living with dementia
What worked well in the past and could improve provision	- holidays arranged by a veteran organisation in hotels specifically for ex service personnel - creating a veteran-specific community of belonging offering support to care partners - reducing the gap in support and joined-up thinking - improving access and ensuring veterans are involved in service design

Qualitative findings (see Table 1 for themes summary)

Analysis of the data from service providers' views about the level of support available for veterans living with dementia in the community revealed four main themes: *complexities of support; what service providers are offering that is working well; challenges in providing support; what worked well in the past and could improve provision*. All quotes have been anonymised and participants assigned pseudonyms.

Complexities of support

Service providers recognised that veterans living with dementia have a variety of needs including financial, emotional, physical and practical care (which clearly can also apply to non-veterans). ***Individualised needs:*** service providers were aware that depending on the type and 'stage' of dementia, each veteran in front of them would require different levels of care (eg, one to one support, respite care). As a result, services needed to respond to each veteran living with dementia on a case-by-case basis rather than a 'one size fits all' approach:

> *"It's definitely not a one size fits all kind of programme in that way so we have to try and make it personal to try and support people as much as possible" (SP1)*
>
> *"We just have to adapt, you know? Everybody's different. If people have different needs then we try to cater for them, you know, to help" (SP4)*

> *"In a more bespoke way of listening to our clients, our patients, to understand about their experiences and adjusting our service to fit and meet their needs really"(SP9)*

Logistics, access and cost: when asked to reflect on some of the challenges veterans might encounter when seeking access to support, service providers emphasised that although some services are available for veterans living with dementia, veterans may not always find them easy to access. Reasons stated for this included logistical challenges, such as the ability to travel to services that are not local; ability to afford travel, or lacking someone to accompany them.

> *"I think the main barrier for me would be logistics, so it [the service] being accessible and being realistic to get to, whether that might require a carer or somebody to go with them, and that might be very difficult because there's a cost associated to that as well which is often funded privately which is really difficult. Obviously, it's the cost of travel provision, physically getting there" (SP01)*

Other challenges included a postcode lottery where certain local areas might be better served and have a variety of services available (eg due to funding availability).

> *"It could be a barrier where they live" (SP09)*

Finally, service providers recognised that services are often not advertised in an appropriate information format for veterans living with dementia, making it unclear for veterans where to access support in the first place.

In general, services are not specifically tailored to meet the needs of veterans living with dementia. These include individuals of various ages and abilities, individuals requiring various levels of support (requiring a care partner, requiring support with transportation, requiring support to engage in activities) as well as individuals presenting with different difficulties based on the type and advancement of their dementia.

Services not specifically designed for veterans living with dementia: Another area highlighted by service providers creating access difficulties was the organisation of the provision. Services would often be community based and open to the whole community, but the service providers concerned were often not aware if services existed that were specifically designed for veterans living with dementia:

> *"I'm unaware of anything specific in [place name] that's for veterans purposely with dementia, there isn't anything" (SP09)*

It would therefore logically follow that if service providers were not aware of any veteran-specific services in their area, then the veterans themselves with dementia would similarly be unaware.

Our findings also indicated that veterans living with dementia can feel out of place when attending community services designed for veterans but not specifically for dementia, or dementia focused services but with no knowledge of veteran issues; these findings would appear to indicate that (some) veterans living with dementia may not attend these services as they do not find them relevant/useful.

Service providers have also found that it is difficult to know if any individuals accessing services are veterans living with dementia due to not always asking the question explicitly. This poses challenges when seeking to offer personalised support and be flexible:

> *"we always used to be very much aware of the people that had come through our service that had served in the forces, they were always very vocal about their experiences and very vocal that they'd served, and I was always very aware, and maybe that's a telling point now that I'm not quite so aware of anybody that comes through our service that has served or are veterans (SP09)*.

What services are offering that is working well

When asked to reflect on what is currently working well for veterans living with dementia, service providers suggested several examples and reasons for that as grouped by theme below.

Social and community groups – the creation of social, peer, and community groups has been effective in providing veterans with a sense of belonging, camaraderie, and support:

> *“This is a service where they can come and they can feel like, you know that they are part of a group again, and you've got friends that they can socialise. It's a lovely feeling” (SP15)*

According to service providers, the ability of veterans to share space with other veterans positively impacted their mood, enabling them to reminisce about their time in the military as well as share and retell stories:

> *“I’m not saying that we’ve got the answers, absolutely not, but I think the community groups will play an important part in intervention care and creating an environment where people can thrive for longer” (SP01)*

Reacting to need and flexible provision **–** it was felt that due to the differing needs of individual veterans living with dementia who seek help, being able to apply support flexibly was essential to ensure the support was relevant and adequate:

> *“That support, it depends on each week because we’re reactive, we’re not proactive” (SP03)*
>
> *“So you react to the need as it comes along” (SP08)*
>
> *“We just have to adapt, you know? Everybody’s different. If people have different needs then we try to cater for them, you know, to help” (SP04)*

Collaborating and signposting - *collaboration* between different service providers and signposting veterans living with dementia to appropriate services was thought to help streamline support:

> *“So, we're sort of feeding them into other places and other support mechanism” (SP12)*

However, an enhanced joined-up system could improve provision according to the service providers interviewed. They also highlighted the need for a point of contact, and a clear and centralised approach to help ensure that veterans living with dementia know where to access and seek support, and be signposted to various specialised services to support their specific needs:

> *"So if we were to have any issues surrounding that I think we'd be well set up to direct people to the right types of places" (SP01)*
>
> *"So, once we've highlighted that that particular organisation might be able to help with what we do here, either generally or specifically, then we'd start making contact and work together" (SP14)*

Challenges in providing support

How to support veterans in generic services: integrating veterans into generic services poses challenges due to their unique needs and experiences. Some service providers argued that veterans can behave differently to the general population; for example, some felt that veterans can be a very 'closed' community/group who develop their own culture and ways of dealing with challenges. Therefore, having veteran specific services could be an advantage to ensure that the service relates to the veteran's sense of identity:

> *I find the veterans are quite different to the rest of the population in general, they have a different attitude to life and they're just different (SP08); it's very different dealing with veterans, is a very different psychological makeup than dealing with somebody else (SP13).*

Based on their interactions with veterans, some service providers argued that veterans living with dementia would benefit from being offered mainstream services and peer support:

> *"It can be hit and miss, some people like it, some people don't. Some veterans feel like they're owed a place on the earth and that there should only be veterans in this club, but it doesn't work. It doesn't work from a business point of view and it doesn't work from what we're trying to achieve, point of view, you know. A lot of people that use this facility have a, you know, have PTSD or regeneration syndrome and stuff like that, where they're trying to settle down and they're struggling to settle down with normal day to day life and stuff" (SP11)*

However, other service providers interviewed recognised that veterans living with dementia present with unique needs and challenges and specific support should be offered:

> *"I don't think we've got anything specific other than what I've said. I think what they want is actually once they get that diagnosis and once they're dealing with it, the families, think sometimes they would like somewhere specific that's veteran-orientated for support rather than just mainstream NHS" (SP10)*

> *"So those people go into the memory tea dances and things, they lived a different life and I think that's why a lot of them feel like they don't fit in when they get a little bit older and bit more confused with their dementia. It doesn't necessarily fit in for them to be in those places, so it would be lovely if there was somewhere that they could go, but I have never come across anywhere" (SP08).*

How to engage care partners: engaging the care partners and families of veterans to ensure they receive adequate support remains a challenge based on the experiences of service providers interviewed. While service providers reported that care partners are needed and are at times essential to veterans living with dementia when accessing services, on occasion, it was recognised that their presence might hinder veterans from fully engaging with services:

> *"A lot of the time we find veterans or not [veterans] that sometimes our person with dementia doesn't really sometimes share how they're feeling and maybe it's twofold for veterans that maybe have some experience that they don't feel able to share with their family members, as well as their worry and concerns about their own diagnosis" (SP09)*

Similarities and differences in support needs**:** there were mixed reports by service providers, with some seeing no discernible support need difference between veterans and non-veterans, while others saw a difference in the way that veterans engaged with the support service, indicating that a nuanced personalised approach to care may be required:

> *"I can't say from my experience. As a dementia advisor, obviously, I come across a lot of people with a diagnosis of a form of dementia, who are also ex-military, or members of their immediate family are ex-military. And I wouldn't say there was any difference to be honest with you" (SP14)*

> *"Yeah, obviously a lot...sometimes it's obviously the lack of confidence, but with the veteran population, they're very insular, and a lot of the veterans will only engage with other veterans. So because they're not specifically veteran-orientated ways of support, they may be more reluctant, because obviously you're dealing with civilians and people like that, that actually a veteran they might be a bit resident – reticent, should I say, to actually engage with that common stream service" (SP10)*

What worked well in the past and could improve provision

Service providers reflected upon aspects of provision that worked well in the past but are no longer available. Some of the reasons for the reduction in service provision included lack of funding resulting in services being cut, or other limitations (eg, COVID impact and individuals no longer attending services).

Holidays arranged by veteran organisations: organising holidays in hotels specifically for ex-service personnel was highlighted as an effective way to provide respite and a sense of community.

> *"The hotels were only for ex-service personnel. So that if they met somebody in there, whether they have dementia, or they didn't have dementia, they would talk about the forces and about their experiences, and about the uniforms...The normality of those hotels, I can't tell you how different it made the men feel, that they were back in in their own place where they found comfort" (SP13)*

***Creating a veteran-specific community of belonging*:** initiatives such as memorabilia and reminiscing sessions, which foster camaraderie and a sense of belonging, were seen as valuable:

> *“With memorabilia in, you know, where they could go and talk to other people that understood what they were talking about” (SP08)*
>
> *“I think things like reminiscence sessions. It is something to draw their past into their presence. That that would be what veterans would ask for as far as my knowledge of what veterans have asked for. It is that connection, so that their dementia journey can take them back” (SP13)*
>
> *“So, I think a massive thing is the camaraderie, belonging to something and not being on their own. It’s massive” (SP12)*

Offering support to care partners: providing targeted support to the care partners of veterans living with dementia was emphasised as crucial for the overall well-being of both veterans living with dementia and their families:

> *“And then we rapidly moved on to working with families and friends and community as well because we realised there was a need there and that people were showing up to that, you know, to that training that we provided, and that all went really well and was very well received” (SP07)*
>
> *“Well, I mean, I think what makes a difference to them is how well we’re looking after the people that care for them “(SP05)*

Reducing the gap in support and joined-up thinking: efforts to reduce gaps in support and ensure more cohesive, joined-up service provision were seen as essential; but it was unclear how this might be achieved – for example a central database was mentioned:

> *“So I think longer term there needs to be a more central, joined up thinking approach to how you create hubs or health hubs that support people with dementia” (SP01)*
>
> *“The thing I find is that, there’s so many services out there, and there’s so many people trying to do a similar thing and things, and it’s hard for, if you’re a veteran, where to turn to” (SP06)*

> *"No, I think there's definitely a gap in the market, so to speak. I think there are definitely a lot of people that need support, and I think that's going to get bigger…" (SP08)*

Improving access and ensuring veterans living with dementia are involved in service design: enhancing access to services and involving veterans living with dementia in the design and delivery of these services were identified as key areas for improvement:

> *"…because there is some fantastic support available, but again, you can't access it if you don't know about it, and if you're not lucky enough to have a network that you know a project or help is there, that's what it comes down to I think" (SP01)*

> *"It's knowledge, knowing we're here and us knowing they're there as well, it's that engagement" (SP03)*

> *"…and I think it's key to getting the right people to run those groups as well that have experience and maybe a background of working with veterans and have a full understanding, maybe veterans themselves running support groups for veterans with dementia I think would be good. Or at least speak with them and find out what they feel would be a good way of supporting people". (SP09)*

PHASE 2

Participants and recruitment

Eleven interviews were completed. Interviews lasted between 32 and 77 minutes. The interviews were guided by a topic-guide and focused on veterans' experiences of receiving a dementia diagnosis, their views on current service provision and support, and their perspectives on how these services could be improved. Six interviews were with veterans living with dementia (four out of the six had care partners or family members present), and five were care partner interviews. All six of the veterans interviewed were white British and aged between 57 and 85 years old; one was a women, five were men and all had received a dementia diagnosis during the last five years. As for care partners, all were aged between 24 and 83 years old and were family members of the veteran with dementia (ie their spouse, child or grandchild). Five identified as white British and female and one identified as black African and male.

Recruitment challenges and corresponding protocol changes

We completed several amendments to increase study participation. These included expanding our potential recruitment pool to across England, updating our inclusion criteria to include nursing and health care professionals who had served (initially we were focused only on veterans who had experienced active combat roles in line with research which indicates such roles carry a higher risk of developing dementia), and veterans who entered residential care within the last three months (although in the end we were unable to recruit anyone in this latter group). We also had problems with ‘fake participants’: we received more than 30 emails and queries from ‘interested’ parties who clearly did not meet the advertised criteria but were presenting as if they did. To prevent fake participants participating in the study, we completed an ethical amendment to update participant procedures to include additional screening steps.

Qualitative findings

As can be seen in Table 2, analysis of the data from veterans living with dementia and their care partners revealed four main themes: *Veteran identity, Challenges in accessing diagnostic services and post-diagnostic services, Barriers to accessing service provision* and *What works well and how can services be improved*.

Table 2: Phase two themes and sub-themes table

Theme	Sub-themes
Veteran identity	• No link between dementia and service history • Remembering life in the military • Stigma and denial of diagnosis
Challenges in accessing diagnostic and post-diagnostic services	• Impact on families • Complexity of diagnostic process • Lack of personal touch • Lack of awareness of services available post-diagnosis
Barriers to accessing service provision	• Impact of COVID • Fragmented and complex system
What works well and how can services be improved	• Veteran specific support • Individualised care and support • Better sign-posting and more ongoing support

Each of the four themes with sub-themes are discussed in turn below. All supporting quotes having been anonymised and participants assigned pseudonyms for data protection reasons.

Veteran identity

No link between dementia and service history**:** all veterans living with dementia were asked whether they thought there was a link between their military service and dementia. Of the six veterans interviewed, not one perceived a direct link between their dementia and their military service:

> *"A long time ago. And just thinking about your time in the WRAF do you think it has any associations with your dementia now, your diagnosis?...No, not at all...Okay, that's fine." (VLWD06 & CP07)*

> *"So, you don't think there's any parallels or connections between serving in the Navy and...No. No, it's just getting old." (VLWD01 & CP01)*

Remembering life in the military: many veterans living with dementia frequently recalled their military experiences, providing a sense of continuity and comfort. These memories were vivid and offered a sense of belonging and camaraderie amidst the cognitive challenges posed by dementia:

> *"And quite often if I meet people who have been in the Forces and we talk about all the different places we went to and all of the things that we had, because really we were treated extremely well in those days, definitely, definitely the best part of my life was in the WRAF." (VLWD06 & CP07)*

> *"It was the best part of my life when I was in there." (VLWD06)*

> *"I enjoy going to the breakfast club, that's good...Well, they all natter on about the Navy anyway when you go there...We've got Army guys and Air Force ones. Not many Air Force, a lot of Army, but not a lot of Air Force." (VLWD03 and CP03)*

> *"He has a very nice young man who's in the Air Force who rings him up every week at six o'clock on a Thursday evening and talks back and forth to him for a whole*

> *hour, and he's lovely. And that comes through the RAF Association. They also send him a magazine, a great big magazine that he can look at and read." (VLWD05/ CP05/ CP06)*

Stigma and denial of diagnosis: from veteran and care partner accounts (the latter relating to the veteran they were caring for), some veterans appeared to harbour internalised stigma associated with their dementia diagnosis. In some participant accounts, the language they used to describe their dementia was very negative. For some veterans, this perception was linked to not accessing dementia specific services, and in one case, not telling other people about the diagnosis. This stigma appeared to lead to denial or delayed help seeking for some veterans interviewed:

> *"Went back to work, didn't tell them" (VLWD04)*
>
> *"Because everything they throw at me, I'm like, no, I'm not taking him into a group where they're all demented, I don't want that. And when I first contacted Help for Heroes, I thought how good it would be for him to have somebody...one of the forces, ex-forces volunteers that would come and visit him and talk to him about the service. And for him to get that stimulation, not in a dementia focused way but in an individual way, that could encompass his needs about the dementia." (CP08)*

Challenges in accessing diagnostic and post-diagnostic services. Participant accounts highlighted four main areas of challenge connected with a dementia diagnosis and accessing appropriate services.

Impact on families: the dementia diagnosis not only affected the veterans but also had a profound impact on their families, who often felt unprepared for the associated challenges with dementia; for example, multiple hospital appointments, lack of services and support, change in personality, and becoming the carer for their loved one:

> *"I think on that first appointment to a brain scan and then the relationship, the difficulty of living with somebody with dementia started from that point onwards because I was seen as the person that was forcing him to go in front of medical professionals. It wasn't his choice. It was mine." (CP01)*

Complexity of diagnostic process: receiving a dementia diagnosis was described as a complex, layered process involving multiple consultations and significant emotional strain:

> *"Really, really angry. And then when we walked out in with shell shock are they gave me a folder with information in it" (CP01)*

Lack of personal touch: veterans highlighted a lack of personal touch in the diagnostic process, which they felt was likely to be due to limited resources and capacity in the healthcare system, but meant that their unique backgrounds and experiences were not sufficiently acknowledged:

> *""...there's a carer's organisation and then there's a lunch club for dementia, but that isn't what was needed or wanted. The hospital and them have tried to pressure me going to a carer's group and I said no, I don't want to go to a carer's group because I don't want to...almost felt like you'd lose your individuality and you'd become part of a system that only talked and thought about dementia..." (CP08)*
>
> *"And it's dementia cafes. That's all. Dementia cafes. Nothing else. And I'm like, well, we're not going there." (CP01)*

Lack of awareness of services post-diagnosis: there was a notable lack of awareness among the veteran participants regarding the services and support available to them post-diagnosis due to what they appeared to feel was a lack of information/ communication at that point leading to feelings of isolation and confusion – and not only for the veteran but for the whole family system:

> *"Nobody told you anything. Most of my information has come from James [family member who is ex-services] because he's Googled it. Nobody tells you anything." (CP02).*

There clearly are services available, but it was reported by some veteran and care partner participants that often only one appointment was offered with little or no follow-up. This is important as it potentially indicates insufficient resources within support systems to be able to offer timely follow-up appointments, or the lack of administrative systems in place to keep track of help-seekers.

Barriers to accessing service provision

Participants commented on barriers experienced when trying to access services.

Impact of COVID: the COVID-19 pandemic and impact thereafter appeared to exacerbate existing barriers, such as a more limited range of specific support groups for veterans living with dementia (including in-person support), and a more disjointed healthcare system which was struggling with capacity and resources:

> *"And I think COVID was a wonderful excuse for everyone to do less than they did. And I know you can wind it back to the government and say these people aren't funded, they're not getting it, they're not...and probably that's where the root of it is, it's not the people individually. But nobody is taking charge of that. So, I think that's what stops it happening. There was a time when organisations were more accountable and that from what I've seen has gone. And where I would condemn the professionals is using weak excuses to explain that or not explaining it at all or just throwing it back in your face. And if you look how responsibilities...again, I'd say like the doctors, those receptionists are so authoritarian that, as I said, it's just asking for trouble, it really is." (CP08)*

Fragmented and complex system: most veteran participants and their care partners found the infrastructure supporting dementia and veteran services to be confusing for various reasons, such as the absence of a centralised system to help overcome what was perceived as being an overly complex and fragmented system, with poor levels of communication and a lack of clarity over which organisations offered support delivery or only signposting services. Overall, such issues made it difficult to navigate and access necessary support:

> *"It would be very hard work setting up because everything is so fragmented, you know. And obviously you've got[service name], you've got [service name], you've got all these different groups that are running things, and then you've got all the private groups." (VLWD06/CP07)*

> *"It just explains what they are. We navigate support avenues through our referral partner's information organisations and local support networks and help bridge the gap between beneficiaries and the appropriate organisations. And I thought well, that's a non-starter because if you have as much luck as I've had trying to enlist any services..." (CP08)*
>
> *"And I said, well, can you come and help me set something up? They went no. We're commissioned to signpost and refer we're not commissioned to deliver" (CP01)*

What works well and how can services be improved

Veteran specific support: while there were services available for dementia, some veterans interviewed felt that these services were not tailored to their specific needs and experiences. They expressed a desire for more veteran-specific support that acknowledged their service history and unique challenges:

> *"I think that's the kind of support people with dementia need and because of the forces background if it was coming from that, especially where it's in people's long-distance past where they are remembering.... And he just...he was full of it, I was in the forces. So, despite many, many years I suppose in the way that your childhood is implanted, the forces are implanted." (CP08)*

Individualised care and support: individualised care for the veteran living with dementia was identified as important:

> *"Education in dementia is such a big thing. And what I like is, what's happening now it's the students that are coming through, the psychologists, are the best thing since my diagnosis. Because they want to learn, they want to know and they talk to you, they listen to you and we're all different." (VLWD04)*

Both care partners and veterans identified the importance of offering various support and activity groups (not necessarily just focused on veteran identity)*:*

> *“He enjoys comedy, he enjoys sport. He enjoys human contact. He enjoys conversation, he enjoys working alongside somebody. So if I asked him to sit down and colour something in, he's not going to do that.” (CP01)*

Some veteran and care partner participants did, however, experience more personalised and practical support and were clearly thankful for this:

> *“The other thing we’ve had done by the veterans [charities] is the ramp to the front door and the front door replaced, and that was all paid for by them.” (VLWD05/CP05/CP06)*

Better sign-posting and more ongoing support

In some cases, veterans and care partners expressed that there were not enough service and support options to choose from, but for others, they felt they were not even aware of the options available. Several participants described the need for better awareness raising of existing services and the support options being offered. This would include better service provider awareness of other services that may have more suitable options for the individual in front of them and to whom they could sign-post the individual:

> *“So I think better communication around not duplicating and enabling would be useful for everybody.”* (CP01)

> *“And if you speak to the charities, they'll say we want more veterans, but we don't know how to get the veterans. The missing gap is the NHS linking them.”* (CP02)

> *“What you need to do is then, you need to have one-to-ones with these people, it doesn’t have to be the same person but you have to go through it with, like, it’s like going back to school. And you have to talk to them, break it down, you’ve got to break it right down to little pieces because it’s alright having, even if you have a carer there.” (SU04)*

PHASE 3

METHOD

The funding was approved shortly after the COVID-19 lock-down. Due to the accessibility advantages of meeting online (and increased use of this medium) one online workshop was planned (and one in-person). At a later stage of the project, we also received feedback from RAG members and other care partners and veterans living with dementia that an online workshop was more flexible for people with caring responsibilities.

We held our first in-person workshop in October 2023. It was attended by 33 key stakeholders. This was a half-day session hosted by the study team at the University of Manchester. Our aim for the day was to share our interim findings and discuss the priorities for practice emerging from our data and participant experiences as well as to discuss the next steps in the project.

Workshop 2 was held remotely via Zoom in April 2024 and was attended by 14 service providers, veterans and care partners. This was a half-day session hosted by the study team. Our aim for the day was to share a study update, interim findings from phase 2, and what remains unanswered from our study findings.

Both workshops were a combination of small group exercises, and larger group prioritisation activity. We asked the groups three questions and together the groups identified several priorities from a list of suggestions. A summary of answers and the priorities are outlined below.

POLICY AND PRACTICE WORKSHOPS

There were two workshops in this phase. During these workshops, the group were asked several questions and to outline priorities for moving forward. These are included below with a summary for each question and the resulting priorities listed.

Key priorities for improving service provision for veterans living with dementia still living in their own homes, and for their care partners, were identified and agreed by the group as follows:

I. Mapping and gathering information about what services are available. Although Veterans' Gateway[2] was cited as a great resource, it was felt that it did not cover services available locally, and if searching using the word 'dementia', no specific organisations came up.
II. Improved and consistent signposting to available services and support (eg, through Memory Assessment Teams and / or GPs).
III. Design, evaluate and provide veteran specific dementia training and coordination across services.
IV. Raise awareness of the importance of providing support for care partners and families.

The purpose of Workshop 2 was to share with the group a study update including interim findings from phase 2, and what remained unanswered from the study findings at that point. As in workshop one, attendees were asked to rank their key priorities and suggest additional priorities if they believed anything was missing.

Key priorities from this workshop and the related priority setting exercise were to:

1. Promote joined-up working across dementia and veteran services.
2. Promote awareness of dementia and dementia services in veteran services and communities.

Support family members and care partners of veterans living with dementia.

Summary from the workshops

- *Asking about veteran identity*

During the workshop discussion, some national areas of good practice were identified in terms of finding out if someone had served previously or not; for example, some Memory Assessment Teams (MATs) asked whether individuals had served in the Armed Forces, and if they had served, referred them on to the Admiral Nurse team. However, it was acknowledged that MATs did not routinely ask about service history – nor (if was felt) did

---

[2] The Veterans Gateway search facility has since moved to Gov.uk (September 2024); thought the Veterans' Gateway helpline does continue to provide information and referral support (https://www.gov.uk/government/collections/find-support-for-veterans-and-their-families)

many community-based services. That said, it was also raised that some veterans may not identify as being ‘a veteran’ even if asked, perhaps due to the time since they had served, or a perception that the length of time was too short to identify in this way. It was suggested that the question ‘Have you ever served in the Armed Forces?’ may be more likely to receive a correct response, or being asked about their service history (as tends to be routine in Veteran Friendly GP practices and gives the provider the information required to sign post on to appropriate services and support).

In addition, ‘veteran identity’ was suggested not to be strong for all veterans, eg where length of service had been very short or was a long time ago, while for others the veteran aspect of their identity remained a vital part of who they felt they still were (even where active service was decades ago). Overall, identifying whether someone had served or not when accessing dementia support was seen as important to enable a service provider to take into account this history when providing support and care.

- *Post code lottery*

There was some discussion around perceived gaps in specialist support, either veteran informed or dementia informed, depending on where veterans lived, meaning that some veterans living with dementia (ie still in their own homes) do not always receive the support they need or could otherwise access if they lived elsewhere.

- *Fragmented Services*

A common point was that of ‘fragmented services’. Some participants suggested this might be a particular issue for veterans living with dementia due to their ‘dual identity’ (ie as both an individual with dementia but also a veteran). This was seen as a possible issue due to the difficulty that exists in terms of services not being informed about dementia and/or veteran issues, and then the veteran living with dementia not knowing what services might be appropriate for either veteran or dementia support.

DISCUSSION

Across all phases of the study, our key findings indicate that veterans living with dementia were experiencing challenges accessing support and services. Veterans, care partners and service providers all mentioned that it seemed hard to navigate the different service options available and that services were not coordinated; for example, veterans' services were not always aware of dementia services and vice versa. Both service providers and veterans were commonly not aware of the services available to veterans living with dementia. Furthermore, veterans and care partners particularly voiced frustration regarding the 'fragmented' nature of service provision. Service providers identified similar issues regardless of their service 'orientation' (ie dementia specific or veteran specific), and added that provision was somewhat precarious at times as many community-based support groups and initiatives relied on short-term funding.

Research shows that veterans have a higher prevalence of PTSD than non-veterans – particularly where they were deployed in combat operations (Sharp et al 2024). Ritchie et al's (2019) thematic scoping review indicated that the PTSD that can be evident in veterans with dementia, poses distinct support needs and care challenges. Veterans who develop dementia may have specific military experiences that they relive; this could include experiences previously coped with and adjusted to (Ritchie et al 2019) but that later re-emerge during their transition to living with dementia. This is important because of the memory changes that occur in most types of dementia, whereby early life experiences (eg teens and 20s) become more vivid and past experiences form a greater part of people with dementia's current reality.

However, PTSD or traumatic experiences were not something discussed by veterans or care partners within this study. Veteran identity, and service experience, were mentioned in a positive way in participant accounts, (eg the camaraderie of serving). Veteran identity and pride in service history was felt to be important by the participants, with many of the veterans and care partners saying how much they appreciated it when support services took this into account; for example, by organising breakfast clubs where they could meet with other veterans.

However, our findings suggest that the intersecting identity of being a veteran (as well as person living with dementia) could at times make it challenging to access services. This was indicated by some of the participant discussions where they used very negative language when talking about their dementia and the diagnosis, did not want to tell people they had a dementia diagnosis, and did not want to use dementia services. Given that the military is widely associated with a culture of stoicism and self-reliance, it would follow that being a veteran, continuing to identify as such and to highly value that identity, together with being diagnosed with dementia, may impact their willingness to admit a need for help and to seek that help (Heward et al 2024). Stigma regarding mental health problems has been found to impact perceptions and help-seeking of UK serving personnel and military veterans (Randles & Finnegan, 2022). Our findings demonstrate that veteran identity is important in relation to seeking help in the following ways: being able to identify services in the first place as providing appropriate support to their dual identity of both living with dementia *and* being a veteran (whether generic services or veteran specific) – such as by illustrating that they understand the need for a sense of belonging and have some awareness of what may be unique support needs for veterans; and being willing to engage with such services (ie not allowing the military culture of stoicism or their own stigma to prevent their coming forward for help).

There are some limitations to this project that impact on generalisability of the conclusions that can be drawn. The key limitation is the relatively small sample of veteran participants living with dementia and their care partners. Although this was an exploratory qualitative study that used a method suited to capturing depth of participant experience (ie reflexive thematic analysis), the intended target number of number of veteran participants to recruit was not reached – likely due to the fact this is a vulnerable population who can be hard to reach. Nonetheless, due to the qualitative exploration of the themes and the multiple phases of the study, the findings offer some valuable insights into the needs of veterans with a dementia diagnosis still living in their own homes, and the perspectives of service providers who operate in this space.

KEY RECOMMENDATIONS

1. IDENTIFY VETERANS [an issue identified in phase 1 and 2 interviews]– this could be achieved by encouraging professionals to ask about service history at appropriate screening points within health and social care. This could be achieved by a greater number of GP practices signing up for the Veteran friendly GP Scheme. In addition, it would be useful if Memory Assessment Teams (who generally conduct dementia diagnoses) to routinely ask about

veteran status. Doing so would enable veterans to be pointed to services that maybe available, such as breakfast clubs, or holidays, that cater to the unique identities of veterans.

2. PROMOTE JOINED-UP WORKING [identified in phase 1 and 2 interviews and algins to workshop 1 identified priorities 1, 2 and 3, and workshop 2 identified priorities 4 and 5] – this could be achieved by enabling and creating opportunities for service providers and those using services to think together about what is required. This would enable proactive discussion about how to reduce gaps in support and ensure more cohesive, joined-up service provision. There are different ways that this can be achieved but a key approach relates to local services being aware of what is on offer and signposting appropriately. A first step to achieving this is by providing dementia training to staff and volunteers working in veterans' services. A second approach would be to ensure those working in generic dementia services are aware of veteran- specific support available in their area and to sign post to these services. It is imperative that there is dialogue and knowledge across the dementia and veteran services to ensure no one falls between the 'cracks' of fragmented provision.
3. SPECIFIC SERVICE OPTIONS [an issue identified in phase 1 and 2 interview as well as workshop 1 identified priorities 1 and 3 and workshop 2 identified priority 1 and 2] - Veterans and care partners particularly felt it would be helpful to have more support options specific to veterans living with dementia. This would, for example, help respond to the needs of veterans who still strongly identify with their veteran status as they may be more willing to seek help from services and peers that understand what they may have experienced/where they may be 'coming from'. Should veterans with dementia relate more to earlier memories than recent ones (as can commonly happen in dementia), such earlier memories may stir up traumatic and distressing events - a service specific to veterans living with dementia may be better prepared to help support such an individual appropriately.
4. PROVISION OF SUPPORT FOR FAMILY MEMBERS AND CARE PARTNERS [issue from phase 1 and 2 interviews as well as priority 4 in workshop 1 and priority 3 in workshop 2] – Enabling the veteran living with dementia to remain in the community and at home often requires the support of family members and care partners. Just as veteran dementia services need to be tailored to recognise *both* the dementia specific *and* veteran identity challenges that present unique support requirements, the family members and care partners of veterans may require support for challenges that symptoms of dementia poses and also the specific need to be able to support a veteran with dementia who may for example relive service experiences. Therefore,

support services, for example, support groups for family members need to be able to acknowledge and provide expertise in relation to particular challenges that may arise in relation to memories of service and how to recognise and provide strategies to support reliving traumatic memories.

5. FURTHER RESEARCH. Further research would help further inform where specific interventions and services for veterans living with dementia need to be developed and offered, and/or (current) policies developed to help ensure this vulnerable cohort is fully supported and at no disadvantage. For example, comparative quantitative work that looks at service use for both veterans living with dementia and the general population diagnosed with dementia. However, quantitative research is not well placed to capture the complexity of identity and service use so additional qualitative research should be conducted with a specific focus on this; if this is the primary focus then directly recruiting from NHS services should be factored into the timeline and funding. There is a pressing need to understand where (if at all) the experiences reported in this study differ or not to those of civilians with dementia to be able to argue for changes in practice in keeping with the Armed Forces Covenant (Ministry of Defence, 2022). It could also to useful to compare the experience of military veterans, with for example the experiences of blue-light service veterans who may experience service-related issues leading to PTSD and reliving of such experiences when dementia emerges.

CONCLUSION

The study was amended in response to challenges recruiting veterans and care partners. However, staff representing veteran and dementia services were both included in the first phase of the study as planned. Although our recruitment numbers were below those anticipated for both phase 1 and phase 2, they were in-line with other exploratory qualitative studies and we generated rich data and subsequent insights from participants in both phases. The workshops enabled a dialogue between different stakeholders about our findings and the implications of these for future policy and practice. Our recommendations highlight four initial areas for action emerging from our findings to enhance the support offered to veterans living with dementia in the future. We also made a 5th recommendation - for future research - to enable the evidence base in this specialised and somewhat neglected area to build. For example, we need to hear from more veterans and their families about their experiences, achieved via a larger and diverse sample, to ensure that service developments are based on identified gaps in support available. There is also a need for work that might provide a comparison about how dementia and veteran support is reported on and provided in other comparable countries; and there is the potential to learn from the support needs of veterans and other blue light service veterans (eg fire service, police) who may similarly experience service-based trauma that leads to specific challenges in supporting their care and wellbeing should they develop dementia. At the current time there is the need for additional robust evidence to better inform policy-makers and practice-providers in prioritising, promoting and commissioning specific support, care and wellbeing to best fit veterans living with dementia.

DISSEMINATION

Presentations:

Innes, A., Morris, L and Churchman A. (2023) *Supporting Veterans Living with Dementia: A UK based study*. Canadian Association of Gerontologists 52nd Annual Scientific & Educational Meeting October 26-28, 2023 | Toronto, Ontario, Canada

Morris, L., Morley, H. and Innes, A. (2024). Supporting veterans living with dementia: A multiphase UK based study. Oral presentation, presented at the Veterans' Mental Health Conference UK Annual Conference, May 2024, London (KCL) UK

Innes, A. Morris, L. and Morley, H. (2024) "*Challenges to providing support to Veterans Living with Dementia: Findings from a multiphase UK based study*". British Society of Gerontology, July 2024, Newcastle, UK

Morris, L., Morley, H. and Innes, A. (2024). Supporting veterans living with dementia: A multiphase UK based study. Oral presentation, presented at the British Association for Behavioural and Cognitive Psychotherapies Annual Conference, July 2024, Manchester UK

Poster presentations:

Morris, L., Churchman, A. and Innes, A. (2023) *Supporting Veterans Living with Dementia: A UK based study.* Dementia Congress (November, 2023), Birmingham UK.

Innes, A., Morris, L and Churchman A. (2023) Supporting Veterans Living with Dementia: A UK based study. 33rd Alzheimer Europe Conference "New opportunities in dementia care, research and policy" in Helsinki, Finland from 16 to 18 October 2023

REFERENCES

Alsawy, S., Tai, S., McEvoy, P., and Mansell, W. (2020). ‘It’s nice to think somebody’s listening to me instead of saying “oh shut up”’. People with dementia reflect on what makes communication good and meaningful. *Journal of Psychiatric and Mental Health Nursing,* 27(2), 151-161.

Bass, D. M., Judge, K.S., Maslow, K., Wilson, N.L., Morgan, R.O., McCarthy, C. A., Looman, W.J., Snow, A. L., and Kunik, M. E. (2015). "Impact of the Care Coordination Program “Partners in Dementia Care” on Veterans' Hospital Admissions and Emergency Department Visits." *Alzheimer's & Dementia: Translational Research & Clinical Interventions* 1.1 13-22

Bergman, B. P., Mackay, D. F., & Pell, J. P. (2023). Dementia in Scottish military veterans: early evidence from a retrospective cohort study. *Psychological Medicine*, 53(3), 1015-1020.

Bowker, R., Calvert, L., Allcroft, F., Bowker, G., Foy, P., Gandy, J., Jones, S., Bushell, S., Clark, A and Innes, A. (2020, Special Issue). ‘Our voice started off as a whisper and now it is a great big roar’: The Salford Dementia Associate Panel as a model of involvement in research activities. *Dementia* DOI: 10.1177/1471301219874225

Baun, V., & Clarke, V. (2022). Conceptual and design thinking for thematic analysis. *Qualitative psychology*, *9*(1), 3.

Chen, Liang-Yu, Lin, Yu-Te, Chen, Liang-Kung, and Loh, Ching-Hui. (2017) "Person-centered Dementia Care for Older Veterans with Dementia in Taiwan: Past, Present and Future." *Geriatrics & Gerontology International* 17.S1: 4-6

Ching-Teng, Yao, Ya-Ping, Yang, Chia-Ju, Lin, and Hsiu-Yueh, Liu. (2020). "Effect of Group Reminiscence Therapy on Depression and Perceived Meaning of Life of Veterans Diagnosed with Dementia at Veteran Homes." *Social Work in Health Care* 59.2: 1-16.

Dewing, J. (2007). Participatory research: a method for process consent with persons who have dementia. *Dementia,* 6(1), 11-25.

Dodd, E., Pracownik, R., Popel, S., Collings, S., Emmens, T., & Cheston, R. (2022). Dementia services for people from Black, Asian and Minority Ethnic and White-British communities: Does a primary care based model contribute to equality in service provision?. *Health & social care in the community,* 30(2), 622-630.

Duran-Kiraç G, Uysal-Bozkir Ö, Uittenbroek R, van Hout H, Broese van Groenou MI. Accessibility of health care experienced by persons with dementia from ethnic minority groups and formal and informal caregivers: A scoping review of European literature. *Dementia*. 2022;21(2):677-700.

Finnegan, A., Finnegan, S., Thomas, M., Deahl, M., Simpson, R.G., and Ashford, R. (2014). The presentation of depression in the British Army. *Nurse Education Today*. 34(1):83-91. doi: 10.1016/j.nedt.2013.02.020.

Gitlin, L. N., Mann, W. C., Vogel, W. B., and Arthur, P. B. (2013). "A Non-pharmacologic Approach to Address Challenging Behaviors of Veterans with Dementia: Description of the Tailored Activity Program-VA Randomized Trial." *BMC Geriatrics* 13.1: 96

Greenberg, N. Stevelink, S., Rafferty, L. Greenberg, K and McKenzie, A. (2020). A case-control study examining the association between service-related mental ill-health and dementia in male military veterans over the age of 65. London: King's Centre for Military Health Research. Accessed via 2020_MIDST_report.pdf (kcmhr.org)

Greig, F., McManus, S., and Fear, T. (2021). Dementia in veterans and non-veterans in England: a cross-sectional survey, *Occupational Medicine*, 71(1), 34–40, https://doi.org/10.1093/occmed/kqaa213

Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field methods*, *18*(1), 59-82.

Harrison, J., Maslow, K., Tambor, E., Phillips, L., Frank, L., Herndon, L., and Epstein-Lubow, G. (2020). Engaging Stakeholders in the Design and Conduct of Embedded Pragmatic Clinical Trials for Alzheimer's Disease and Alzheimer's Disease–Related Dementias. *Journal of the American Geriatrics Society (JAGS), 68*(S2), S62-S67.

Heward, C., Li, W., Tie, Y.C., and Waterworth, P. (2024). A Scoping Review of Military Culture, Military Identity, and Mental Health Outcomes in Military Personnel, *Military Medicine*, Volume 189, Issue 11-12, November/December 2024, Pages e2382–e2393, https://doi.org/10.1093/milmed/usae276

Hutchinson, D. (2018). I Want to Empower Families Struggling with Dementia. *Nursing Standard*. 33.7: 51

Kornblith, E., Peltz, C.B., Xia, F., Plassman, B., Novakovic-Apopain, T., and Yaffe, K. (2020). Sex, race, and risk of dementia diagnosis after traumatic brain injury among older veterans *Neurology*, 95 (13) e1768-e1775; DOI: 10.1212/WNL.0000000000010617

Lourida, I., Abbott, RA., Rogers, M., Lang, IA., Stein, K., Kent, B. & Thompson Coon, J. (2017). Dissemination and implementation research in dementia care: A systematic scoping review and evidence map. *BMC Geriatrics, 17*(1), 147.

Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample size in qualitative interview studies: guided by information power. *Qualitative health research*, *26*(13), 1753-1760.

Miles, M.B., Huberman, A.M. and Saldana, J. (2014). *Qualitative Data Analysis: A Methods Sourcebook*. Sage, 3rd Edition, Arizona State University, United States of America.

Mileski, M., Scott Kruse, C., Brooks, M., Haynes, C., Collingwood, Y., and Rodriguez, R. (2017). Factors Concerning Veterans With Dementia, Their Caregivers, and Coordination of Care: A Systematic Literature Review. *Military Medicine* 182.11: E1904-1911.

Ministry of Defence (2022). The Armed Forces Covenant Duty Statutory Guidance https://www.gov.uk/government/publications/armed-forces-covenant-duty-statutory-guidance [accessed 22 January 2025].

Oster, C., Morello, A., Venning, A., Redpath, P., & Lawn, S. (2017). The health and wellbeing needs of veterans: a rapid review. *BMC psychiatry*, *17*, 1-14.

Pickett, J., Bird, C., Ballard, C., Banerjee, S., Brayne, C., Cowan, K., ... Walton, C. (2018). A roadmap to advance dementia research in prevention, diagnosis, intervention, and care by 2025. *International Journal of Geriatric Psychiatry*, https://doi.org/10.1002/gps.4868

Rafferty LA, Cawkill PE, Stevelink SAM, Greenberg K, Greenberg N. (2018). Dementia, post-traumatic stress disorder and major depressive disorder: a review of the mental health risk factors for dementia in the military veteran population. *Psychol Med*. 48(9):1400-1409. doi: 10.1017/S0033291717001386. Epub 2018 Mar 8. PMID: 29514722; PMCID: PMC6088525.

Randles, R., & Finnegan, A. (2022). Veteran help-seeking behaviour for mental health issues: a systematic review. *BMJ Mil Health*, 168(1), 99-104.

Ritchie, K., Cramm, H., Aiken, A., Donnelly, C., and Goldie, K. (2019). Post-traumatic Stress Disorder and Dementia in Veterans: A Scoping Literature Review. *International Journal of Mental Health Nursing* 28.5: 1017-031.

Sharp, M., Franchini, S., Jones, M., Leal, R., Wessely, S., Stevelink, S.A.M, and Fear, N.T (2024). https://kcmhr.org/pdf/Phase_4_Health_and_Wellbeing_Cohort_Study_Report.pdf (accessed 18 February 2025)

Snyder, H.M., Carare, R.O., DeKosky, S.T., de Leon, M.J., Dykxhoorn, D., Gan, L., Gardner, R., Hinds, S.R., Jaffee, M., Lamb, B.T., Landau, S., Manley, G., McKee, A., Perl, D., Schneider, J.A., Weiner, M. Wellington, C., Yaffe, K., Bain, L., Pacifico, A.M., and Carrillo, M.C. (2018). Military-related risk factors for dementia *Alzheimer's & Dementia,*14(12),1651-1662, doi.org/10.1016/j.jalz.2018.08.011.

Stevelink, S. A., Jones, M., Hull, L., Pernet, D., MacCrimmon, S., Goodwin, L., ... & Wessely, S. (2018). Mental health outcomes at the end of the British involvement in the Iraq and Afghanistan conflicts: a cohort study. *The British Journal of Psychiatry*, *213*(6), 690-697.

Weiner, M.W., Friedl, K.E., Pacifico, A., Chapman, J.C., Jaffee, M.S., Little, D.M., Manley, G.T., McKee, A., Petersen, R.C., Pitman, R.K., Yaffe, K., Zetterberg, H., Obana, R., Bain, L.J., Carrillo, M.C. (2013). Military risk factors for Alzheimer's disease. *Alzheimers Dement*ia. 9(4):445-51. doi: 10.1016/j.jalz.2013.03.005.

Williamson, V., Greenberg, N., & Stevelink, S. A. (2019). Perceived stigma and barriers to care in UK Armed Forces personnel and veterans with and without probable mental disorders. *BMC psychology*, 7, 1-7.

Xue C., Ge Y., Tang B., Liu Y., Kang P., Wang M., Zhang L. (2015). A meta-analysis of risk factors for combat-related PTSD among military personnel and veterans. *PLoS ONE*, 10(3), Article e0120270.

Yaffe, K., Vittinghoff, E., Lindquist, K., Barnes, D., Covinsky, K. E., Neylan, T., ... & Marmar, C. (2010). Posttraumatic stress disorder and risk of dementia among US veterans. *Archives of general psychiatry*, *67*(6), 608-613.

Zhu, C. W., Penrod, J. D., Ross, J.S., Dellenbaugh, C., and Sano. (2009). Use of Medicare and Department of Veterans Affairs Health Care by Veterans with Dementia: A Longitudinal Analysis. *Journal of the American Geriatrics Society* (JAGS) 57.10: 1908-914.

Appendix A

Prompt: this follows the participant providing their informed consent to take part.

Welcome *"Hello, I'm [ ] and my role in the research project exploring the service needs of veterans living with dementia is to have the pleasure of talking to you today! Thank you so much for taking the time to participate in this study*

Please keep in mind you can end the interview at any point. As discussed previously, I would like to audio record the interview so that I can make notes later.

Before we begin have you got any questions?"

The interviews will explore the following broad areas:

1. Participants views on the current service provision and support available for veterans living with dementia. And their families.

Prompts:

- Do you have much contact with veterans living with dementia and their family?
- Does the service you work for provide any support services for veterans living with dementia? This could include groups / services specifically for veterans living with dementia, or more general services that veterans living with dementia attend
- Are you aware of support services for veterans living with dementia that are provided by external organisations? Ideally this would focus on groups / services specifically for veterans living with dementia, but could also include more general services that veterans living with dementia attend
- Do you think that the services or groups that you are aware of are likely to meet the needs of veterans living with dementia?
- Do you have any examples from where you work (or elsewhere) of what you consider to be high quality support for veterans living with dementia in the community and their families?

2. Participant views on how the current service provision could be improved

- Do you think that the services or groups for veterans living with dementia could be improved?
- Do you think that veterans living with dementia can easily access general groups and services either for people living with dementia or for veterans?
- Are there any specific ways in which you think services for veterans living with dementia could be improved?
- Can you see any barriers to implementing such improvements to services for veterans living with dementia?

Appendix B

Prompt: this follows the participant providing their informed consent to take part.

Welcome *"Hello, I'm [ ] and my role in the research project exploring the service needs of veterans living with dementia is to have the pleasure of talking to you today! Thank you so much for taking the time to participate in this study.*

Can I please check that you are OK with me recording this interview? As discussed previously, I would like to audio record the interview so that I can make notes later.

Please keep in mind that we can take a break at any time and as many breaks as you might need to. Please let me know that we can stop the recording at any time, and if you wish you can ask me to delete the interview.

Before we begin have you got any questions?"

1. **Experience of receiving a diagnosis of dementia as a veteran**

Prompts:

- can you remember when you first identified that you were having problems with your memory?
- what events led to you seek help? Eg family concerned, worried about memory, worried about other cognitive issues)
- how long have you had a diagnosis of dementia?
- what was your experience of getting a diagnosis? (time, delays, who gave the diagnosis)

- How did receiving a diagnosis of dementia after serving impact you?
  - how long after you stopped serving did you receive the dementia diagnosis?
  - do you think there are any associations between serving and your dementia diagnosis?
  - how did this impact you? / what changed after the dementia diagnosis?

2. **Views on the current service provision and support available for veterans living with dementia.** And their families.

Prompts:

• <u>Do you currently access </u>any services offering support for veterans living with dementia and their family?

- Are these specifically aimed at veterans?
- Are these specifically aimed at individuals living with dementia?
- What services are there?
- How did you hear about them?
- How often do you engage with them?
- How long have you been receiving this support (ask for every type identified)

• Are you aware of any/other services providing support for veterans living with dementia? This could include groups / services specifically designed for veterans living with dementia, or more general services that veterans living with dementia might attend

If so and you chose not to attend, why not? What makes this type of support not suitable for you?

• Do you think that the services or groups that you are aware of are likely to meet the needs of veterans living with dementia?

• Do you have any examples of what you consider to be high quality support for veterans living with dementia in the community and their families?

3. **Views on how the current service provision could be improved**

• Do you think that the services or groups for veterans living with dementia could be improved?

- How?
- In what way?
- What is missing?
- What would help?

• Do you think that veterans living with dementia can easily access general groups and services either for people living with **dementia**

Do you think that veterans living with dementia can easily access general groups and services **for veterans**?

• Are there any specific ways in which you think services for veterans living with dementia could be improved?

• Can you see any barriers to implementing such improvements to services for veterans living with dementia?

Any other points you wanted to raise with us?

Thank participants and outline the next steps in study (diary and follow up interview).

Appendix C

Before we begin have you got any questions?

The interviews will explore the following broad areas:

1. <u>Experience of supporting a veteran receiving a diagnosis of dementia</u>

Prompts:

- can you remember when you first realised that they were having problems with their memory?
- what events led to them seeking help? Eg family concerned, worried about memory, worried about other cognitive issues)
- how long have they had a diagnosis of dementia?
- what was their experience of getting a diagnosis? (time, delays, who gave the diagnosis)
-

- How did receiving a <u>diagnosis of dementia after serving impacted them</u>?
  - how long after they stopped serving did they receive the dementia diagnosis?

  - do you think there are any associations between them serving and the dementia diagnosis?

  - how did this impact them? / what changed after the dementia diagnosis?

2. Participants views on the <u>current service provision and support available</u> for veterans living with dementia. And their families.

Prompts:

• Does the veteran you support <u>currently access any services offering</u> support for veterans living with dementia and their family?

- Are these specifically aimed at veterans?
- Are these specifically aimed at individuals living with dementia?
- What services are there?
- How did you hear about them?
- How often do you engage with them?
- How long have they been receiving this support (ask for every type identified)?

• Are you aware of <u>any/other services providing</u> support for veterans living with dementia? This could include groups / services specifically for veterans living with dementia, or more general services that veterans living with dementia might attend

If so and the veteran you support <u>chose not to attend, why not</u>? What made these services/support <u>not suitable</u> for them?

• Do you think that the services or groups that you are aware of are <u>likely to meet the needs of veterans living with dementia</u>?

• Do you have any examples of what you consider to be <u>high quality support</u> for veterans living with dementia in the community and their families?

3. Participants views on how the <u>current service provision could be improved</u>

• Do you think that the services or groups for veterans living with dementia could be improved?

- How?
- In what way?
- What is missing?
- What would help?

• Do you think that veterans living with dementia can easily access general groups and services either for people living with dementia or veterans?

• Are there any specific ways in which you think services for veterans living with dementia could be improved?

• Can you see any barriers to implementing such improvements to services for veterans living with dementia?

Any other points you wanted to raise with us?

Thank participants and outline the next steps in study (summary of results and workshops).