

Dementia Training Study Centres are
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Veterans with PTSD and Dementia Scoping Study: Final Report

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SECTION 1. Executive Summary

Recently, two large scale studies have reported an approximate doubling of dementia in older veterans with a history of post-traumatic stress disorder (PTSD), suggesting it may be an important risk factor for dementia. There is also some evidence to suggest that Behavioural and Psychological Symptoms of Dementia (BPSD), frequent amongst patients with dementia, are manifested differently in veterans with a history of PTSD, and that veterans with dementia may experience trauma-related re-enactments. The evidence, however, is unclear and the magnitude of these problems is unknown.

Given that the number of veterans with dementia is likely to increase in the near future, in association with population ageing, it was considered important to obtain information to further clarify these issues. Accordingly, we conducted a scoping study to determine whether veterans with a history of PTSD display symptoms of dementia differently to those without PTSD, and identify what (if any) issues this creates for carers, and what strategies, if any, carers find useful to address these issues.

To inform the planning, implementation and evaluation of the project and dissemination of the findings, an advisory group was established in early 2014 to lead the project. Members of the advisory group included representatives of leading dementia and aged care service providers in Australia with contemporary knowledge and expertise regarding key issues in relation to BPSD and dementia care. Specifically, the advisory group considered and provided input regarding the aims, objectives and parameters of the project and contributed to the development of the survey.

Project methods included consultation with several Commonwealth Government Departments and the development and dissemination of surveys for healthcare staff and managers/ senior Residential Aged Care Facility (RACF) staff. Two separate, parallel online surveys were developed. The first survey was for healthcare staff who provide direct care to people with dementia, either in the community or residential care settings while the second was designed for managerial or senior staff working in RACFs. Similar questions were included in both surveys, although they were tailored to address each group's circumstances. The surveys, which were completed anonymously and which required approximately 5-10 minutes to complete, were widely disseminated throughout Australian networks and were open for completion throughout June to August 2014. Ethics approval for the project was obtained from QUT's Human Research Ethics Committee prior to survey distribution.

Requests for relevant data were also submitted to the Australian Institute of Health and Welfare (AIHW) National Aged Care Data Clearinghouse, and the Departments of Social Services (DSS) and Veterans' Affairs.

Summary of Results

Almost six hundred surveys were returned from individual healthcare workers who care for older people with dementia (401) and managers and senior administrative RACF staff (197). While this represents a low response rate (8.6%), common in online surveys of healthcare professionals, it nevertheless provides important data regarding the expression of BPSD in veterans with dementia, with and without a history of PTSD. Survey results indicated that a substantial minority of older people with dementia who receive

care, either in the community, hospital or in a residential care setting, are war veterans. Of those, a substantial minority had seen active military service in a war zone and a substantial minority had a past history of PTSD (although it is not known whether these are one and the same). Most respondents (66% of individuals and 72% of managers/ senior RACF staff) reported that veterans with dementia and PTSD had more severe BPSD and were more difficult to calm and settle than clients with dementia but who did not have PTSD. Symptoms reported to be more severe in those with a history of PTSD included increased agitation, anxiety and fearfulness, delusions, hallucinations and reliving traumatic experiences, increased verbal and physical aggression (with, on rare occasions, the potential for serious consequences), as well as nightmares and sleep disturbances.

A minority of respondents (28% of individuals and 17% of managerial/ senior RACF staff) reported that some of their veteran clients with dementia appeared to have relived a traumatic military experience over the past month. While the majority of such episodes were generally of short duration (most lasted from around 5-10 minutes to 1-2 hours), they were associated with significant distress in those who experienced them with symptoms of severe anxiety, agitation and fearfulness being paramount. Both individuals and managers/ senior RACF staff reported using a range of strategies that were effective in assisting the veteran to calm down following such an episode. The most frequently reported strategies were providing reassurance that the veteran was safe, talking calmly and quietly or distracting the veterans by taking him to another room or quiet place or changing the topic of conversation.

While the AIHW and the DSS responded to our requests for data, neither organization was able to provide any data regarding veterans' prior PTSD diagnosis or active military service and hence could not be used to address our key questions and were therefore not included in this report.

Conclusions

It is concluded that BPSD appears to be more severe in a minority of veterans with dementia and a past history of PTSD. While this is an issue for a minority of older veterans with dementia and their carers, the results show that the symptoms are extremely distressing for those affected and are challenging to manage.

On the basis of the survey findings, the following recommendations have been made:

Recommendations

1. It is recommended that all healthcare personnel who care for older people with dementia as well as facility managers and administrators be made aware of the likelihood that some of their clients will be war veterans who may have witnessed traumatic events during their war service which may influence the expression of BPSD. Similarly, PTSD secondary to other traumatic experiences (non-war related) may also influence the expression of BPSD in people with dementia and care and facility staff should also be cognizant of this possibility. Awareness of this issue is particularly important for RACF managers and administrators who are responsible for staff rosters as well as for non-Caucasian staff, as a minority of older veterans with dementia

may react negatively, suspiciously or aggressively towards Non-Caucasian staff. In particular, some older veterans may react negatively to staff of Asian appearance - a legacy of Australia's involvement in conflicts in South-East Asia (e.g. Japan, Vietnam, Korea etc). Accordingly, a sensitive and appropriate management strategy is required.

2. Given that BPSD appears to be a significant issue for a minority of veterans with PTSD only, it is unlikely that the development of a comprehensive stand-alone educational package for healthcare staff is required. Nevertheless, the inclusion of a module specifically addressing serious BPSD for war veterans and other trauma survivors (including potential preventive and management strategies) within existing resources (e.g. Behaviour Management: A Guide to Good Practice. Managing Behavioural and Psychological Symptoms of Dementia. DCRC-ABC, University of New South Wales; 2012), is likely to be useful. Such a resource should include details of the symptoms displayed and potential triggers as well as appropriate and effective management strategies, particularly as physical aggression has the potential for serious consequences.
3. As the research evidence regarding the relationship between the expression of BPSD and PTSD in veterans is limited, and given this may become an issue of considerable magnitude in the foreseeable future as the number of older veterans increases, it is recommended that further research be undertaken to further clarify any such relationship. The addition of questions regarding veterans' prior PTSD diagnosis and active military service to existing data collection tools (e.g. the Aged Care Funding Instrument) is likely to be a cost-effective method of obtaining the necessary data to explore this question. Issues particularly relevant for the DTSCs include the identification of the most effective and appropriate management strategies for BPSD in this population. In addition, the usefulness of environmental and other interventions to prevent the escalation of BPSD that is both distressing for the veteran and challenging for staff to manage, ought to be explored.

GLOSSARY

ABS	Australian Bureau of Statistics
ACAT	Aged Care Assessment Team
ACFI	Aged Care Funding Instrument
ACQ	Aged Care Queensland
AIHW	Australian Institute of Health and Welfare
BPSD	Behavioural and Psychological Symptoms of Dementia
DCRC	Dementia Research Collaborative Research Centre
DBMAS	Dementia Behaviour Management Advisory Service
DSS	Australian Government Department of Social Services
DTSC	Dementia Training Study Centre
DVA	Australian Government Department of Veterans Affairs
PTSD	Post Traumatic Stress Disorder
SD	Standard Deviation
UQ	The University of Queensland
QUT	Queensland University of Technology
QLD DTSC	Queensland Dementia Training Study Centre
QH	Queensland Health
RACF	Residential Aged Care Facility

SECTION 2. INTRODUCTION

2.1 Background

Post Traumatic Stress Disorder (PTSD) is a common psychiatric condition and often occurs in veterans returning from combat, with as many as 21% of Australian veterans of the Vietnam war thought to have had the condition at some point in their life (O'Toole et al., 1998). Recently, two large scale studies have reported an approximate doubling of dementia in older veterans with a history of PTSD suggesting it may be an important risk factor for dementia (Yaffe et al., 2010; Qureshi et al., 2010). There is also some evidence to suggest that Behavioural and Psychological Symptoms of Dementia (BPSD), frequent amongst patients with dementia, are manifested differently in veterans with a history of PTSD, and that veterans with dementia may experience trauma-related re-enactments. For instance, Australian researchers recently reported that veterans displayed higher levels of physical aggression and BPSD than non-veterans, and veterans with PTSD had higher BPSD scores than veterans without PTSD (Dunt et al., 2012). The study used data collected from carers and case managers of 40 male veterans and 96 male non-veterans living in the community. The authors recommended that these differences be further investigated as the evidence is unclear and the magnitude of these problems is unknown.

This issue is of utmost importance to the many thousands of Australian war veterans. Australian Government Department of Veteran's Affairs (DVA) data shows that, at March 2014, 72,635 male veterans were receiving a service pension from the DVA and their families as well as those involved in conflicts elsewhere. Furthermore, the numbers of veterans with dementia is likely to increase in the near future, in association with population ageing, hence clarification of any relationship between PTSD and dementia requires immediate attention. This has been recognized by the Australian Government as an area requiring additional investigation and support under the "Living Longer, Living Better" Aged Care reforms announced in April 2012 and has been identified by the Department of Health and Ageing as a significant priority area for the Dementia Training Study Centres (DTSCs).

A comprehensive literature review of the published and grey literature recently conducted by our group (Travers, 2014) revealed limited research evidence in relation to these questions. It was reported that some (limited) evidence suggests that veterans with dementia and a history of PTSD exhibit more BPSD including physical aggression than veterans with dementia but without a history of PTSD, although the evidence is unclear. There are also reports that veterans with dementia may experience trauma-related re-enactments. It was recommended that a scoping study of aged care providers and staff be conducted to clarify the issue of BPSD and its manifestations in veterans in comparison to the rest of the population and any associated difficulties faced by care-givers. Another important area for investigation is whether BPSD in this population requires different management strategies than BPSD in other groups.

2.2 Project Aims and Objectives

Hence, the aims of this project were to undertake a scoping study of aged care providers and staff to determine whether veterans with a history of PTSD display symptoms of dementia differently to those

without PTSD, and identify what (if any) issues this creates for carers, and what strategies, if any, carers find useful to address these issues.

Specifically, the following key questions were addressed:

1. Does dementia manifest differently in veterans with a history of PTSD than in other populations?
2. If yes, how is dementia manifested in veterans with PTSD and what issues does this create for their carers?
3. If yes, what strategies do carers find useful to manage these symptoms?

The findings from this project will be used to inform future DTSCs activities in this area at a national level.

2.3 Project Advisory Group

To inform the planning, implementation and evaluation of the project and dissemination of the findings, an advisory group was established in early 2014 to lead the project. Members of the advisory group included representatives of leading dementia and aged care service providers in Australia with contemporary knowledge and expertise regarding key issues in relation to BPSD and dementia care. In addition, they had established links with the broader health, aged care and/or community services sectors.

The Project Advisory Group considered and provided input regarding the aims, objectives and parameters of the project. The group also provided input into the breadth and intended scope of the survey and contributed to the development of specific survey questions.

Members of the Advisory Group included:

- Professor Elizabeth Beattie, Director of the Dementia Collaborative Research Centre; Carers and Consumers, and the Queensland Dementia Training Study Centre (Qld DTSC),
- Mrs Sandra Jeavons, Centre Manager, Qld DTSC
- Dr Catherine Travers, Project Coordinator, Qld DTSC
- Professor Nancy A. Pachana, School of Psychology, University of Queensland (UQ)
- Associate Professor, Christine Neville, School of Nursing & Midwifery, UQ
- Associate Professor Peter Nasveld, Director, Centre for Australian Military and Veterans' Health
- Colleen Doyle, Catholic Homes, Victoria
- Jillian Jeffrey, RSL Care
- Heather Campbell, Dementia Behavior Advisory Management Service (DBMAS)
- Lynne Terry, Mental Health Policy Section, DVA

Regular contact between members of the advisory group was maintained via email and telephone throughout the project.

2.4 Target Audience

The project's target audience were managerial and healthcare staff in a range of settings who were likely to be in a position to provide reliable information regarding the expression of BPSD in people with dementia, as well as any issues this creates for caregivers. As people with dementia live in both community and residential care settings (usually those with more severe dementia), it was considered important to obtain information from staff in both settings, as the expression of BPSD may differ according to the stage and severity of dementia. It was considered that (a) managerial or senior staff working in Residential Aged Care Facilities (RACF) and (b) healthcare staff who provide direct care to people with dementia, either in the community or residential care setting, would be best placed to provide the desired information.

SECTION 3. PROJECT METHODOLOGY

Project methods included consultation with relevant Commonwealth Government Departments and the development and dissemination of brief online surveys for healthcare managers and staff. The study used survey methodology and an online survey was created using Key Survey – the official QUT web-based survey creation and management system. The survey was designed to be as brief as possible and to be completed anonymously. While no personally identifying information was collected in the survey, participants were asked to provide basic demographic data including age, the state or territory in which they worked and their position within the workforce. The survey was widely distributed, via email, to healthcare staff across Australia.

3.1 Consultations

To identify any relevant data that might usefully assist us to answer the key study questions, consultations with the following Commonwealth Government Departments were conducted:

- The Australian Institute of Health and Welfare (AIHW),
- The Department of Veterans Affairs Australia (DVA), and
- The Department of Social Services (DSS; formerly Department of Health and Ageing)

3.2 Survey Development

Survey items, designed to capture the information identified in the project aims, were initially identified by members of the advisory group and the Project Coordinator. Initial drafts of the survey questions were prepared by the Project Coordinator and distributed to members of the advisory group to ensure the survey included questions/items to capture all required data, yet remained brief. The survey was also distributed to members of the advisory group and associates to ensure the wording of the questions was clear and readily understandable. Re-wording was undertaken, as required. An online version of the survey, that could be distributed via email, was subsequently developed using QUT's web-based survey system, Key Survey.

Two separate, parallel surveys were developed: the first survey (Survey 1) was an 18-item survey for healthcare staff who provide direct care to people with dementia, in either the community or residential care setting while the second survey (Survey 2) was a 16-item survey for managerial or senior administrative staff working in Residential Aged Care Facilities (RACFs). Both surveys included questions designed to capture brief demographic characteristics of the respondents including their occupation or role within the organization, type of work setting (community, RACF, other), and gender (individual survey only). Survey questions, as well as characteristics of the clients for whom they cared including the numbers of clients who were veterans, percentages who saw active military service and who had diagnoses of dementia and PTSD. In order to determine how well individual healthcare workers knew their clients with dementia, the survey for individuals also included a question regarding the frequency with which they usually see those clients. In both surveys, respondents were asked whether any of the veterans with dementia for whom they cared, had appeared to relive a traumatic military experience

over the past month. If the response was in the affirmative, the respondent was also asked to provide details of such episodes including the frequency with which such episodes occurred, descriptions of episodes as well as any strategies they found were effective in calming the veteran following such an episode. The final question in both surveys asked respondents to indicate, whether, in their experience, the BPSD displayed by veterans with dementia and a past diagnosis of PTSD differed to BPSD displayed by others with dementia but without PTSD.

On the basis of advice received by the Department of Veterans Affairs (DVA) by a member of the Advisory group (Colleen Doyle), a veteran was defined as all males with white, gold and orange cards OR other DVA entitlement while female veterans were those with white or orange cards.

Copies of the surveys are included at Appendix A and B.

3.3 Ethics Approval

Prior to survey distribution, the project received ethics approval from the Queensland University of Technology (QUT; QUT Ethics Approval Number 1400000428). A separate Consent Form was not required as completion of the survey was considered to constitute consent.

3.4 Survey Distribution

Both surveys were distributed widely to individuals and healthcare organizations that care for older people with dementia across Australia, using a variety of avenues. Survey 1 was distributed to individual healthcare personnel who provide care for older people with dementia, either in Residential Aged Care Facilities (RACF) or in their own homes in the community while Survey 2 was distributed to managers and senior RACF staff. The surveys were distributed via email, in the first instance, to people whose contact details were listed on the National DTSC contact database. This database includes the contact details of people (individuals and managers) who have expressed an interest in dementia education and training conducted by the DTSCs and include contact details for around 3,500 individuals. In addition, the Australian Government Department of Social Services (DSS) provided us with comprehensive lists of the email addresses of managers and senior administrative staff working in all Australian RACFs. Those lists provided around 2,500 unique email addresses to which Survey 2 was sent.

Both surveys were also distributed, via email to people whose contact details were listed on the DTSC partner organization's (e.g. RSL Care, DBMAS) databases while Professor Nancy Pachana (member of the Project Advisory Group) also sent Survey 1 via email to members of the Australian Psychological Society (APS) interest group on Ageing (approximately 370 members).

Finally, the survey was widely advertised on a range of relevant websites and social media pages including the DCRC and DTSC websites, Facebook and Twitter pages, the DBMAS Facebook page, Alzheimer's Australia webpage, the Australian Association of Gerontology (AAG) webpage, the Australian and New Zealand Society for Geriatric Medicine (ANZSGM) webpage.

The survey was open for completion for two months from the 18th June 2014 until the 16th August 2014 and an email reminder was sent to potential respondents approximately one month following the initial email request.

3.5 Formal Data Requests

In addition, a data request was submitted to the AIHW National Aged Care Data Clearinghouse for data regarding the expression of BPSD by permanent residents of RACFs. The Clearinghouse is a data repository that includes data relating to RACFs and residents' characteristics which is collected by the Commonwealth Government (Department of Social Services; DSS) using the Aged Care Funding Instrument (ACFI) and is made available to the AIHW. The ACFI is primarily used to allocate funding to residential aged care providers on the basis of each resident's dependency and associated daily care needs. The ACFI consists of twelve care need questions including verbal (e.g. verbally disruptive behaviour that is severe enough to require staff intervention), and physical behaviour (e.g. physically disruptive or socially inappropriate behaviour that is severe enough to require staff intervention) problems. Diagnostic information about mental and behavioural disorders and other medical conditions is also collected. An ACFI is completed when a person is newly admitted as a permanent resident to a residential aged care facility or if they are an existing resident, when their dependency level changes. Data were requested regarding verbal and physical behaviour problems expressed by residents according to gender, dementia diagnosis and DVA status for the years 2010-2012 (the latest available).

A data request was also submitted to the DSS for data in relation to residents receiving community care services. All people receiving community services must first be assessed by an Aged Care Assessment Team (ACAT) to identify their eligibility for services and the type of services required. Data regarding whether the client has a diagnosis of dementia is recorded as is DVA status. Accordingly, data were requested regarding diagnoses of dementia and PTSD according to gender and DVA status for the years 2009-2013 (the latest available).

Following advice received from the DVA that the department does not maintain databases that allows for veterans with dementia to be identified, no data requests were submitted to the DVA.

3.6 Data Management

Survey responses and data tables were stored on a database on the Qld DTSC secure site located on the QUT's server. The site was password protected and only personnel directly involved in the research project had access to the data. Analysis, under the direction of the investigators was performed at QUT by the Project Coordinator.

3.7 Data Analysis

Quantitative data are presented as descriptive data only while free text responses were categorized according to the reported BPSD or strategies employed to calm residents following a reliving experience, and the number of responses in each category were subsequently counted, and totals reported.

SECTION 4. RESULTS

4.1 Survey Responses - Responses of Individual healthcare staff who care for people with dementia

4.1.1 Demographic characteristics of individual respondents

Four hundred and one individual healthcare staff who provide direct care to people with dementia responded to the survey, and their demographic characteristics are displayed in Table 1. While each Australian State and Territory was represented, the majority of respondents (261; 65%) worked in Queensland, while the ACT and the Northern Territory had the least representation (1% in each case) – see Figure 1.

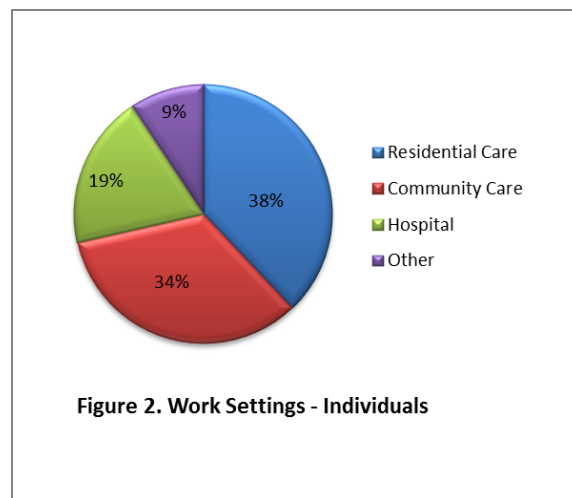
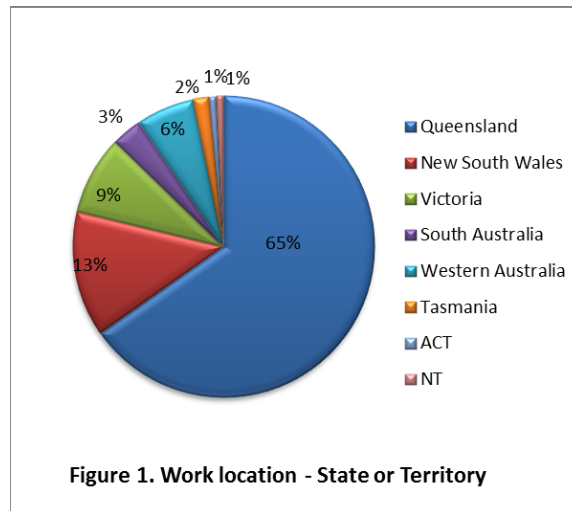
Table 1: Demographic characteristics of individual survey respondents

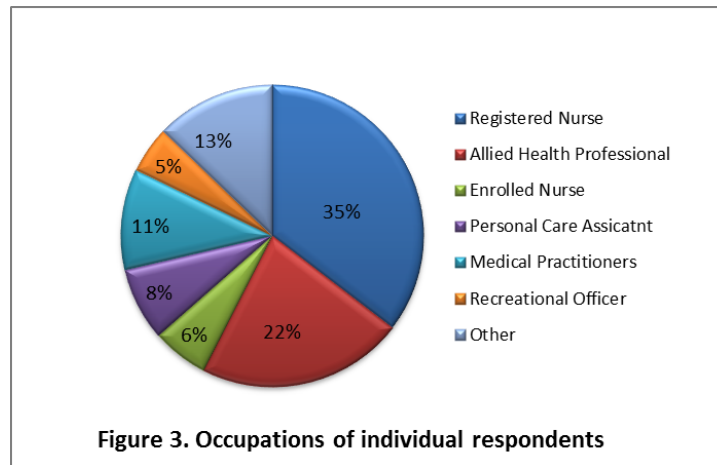
Respondent Characteristic	Response – Number (%)
State/ Territory where respondent works (Total n = 400) [#]	
Queensland	261 (65.2)
New South Wales	54 (13.5)
Victoria	34 (8.5)
Western Australia	25 (6.2)
South Australia	13 (3.2)
Tasmania	7 (1.8)
ACT	3 (0.8)
Northern Territory	3 (0.8)
Gender (Total n = 397)	
Female	354 (89.2)
Male	43 (10.8)
Work setting (Total n = 396)	
Residential Aged Care	150 (37.9)
Community Care	133 (33.6)
Hospital setting (acute, sub-acute)	76 (19.2)
Other*	37 (9.3)
Occupation (Total n = 398)	
Registered Nurse	141 (35.4)
Allied Health Professional	88 (22.1)
Enrolled Nurse	24 (6.0)
Personal Care Assistant	31 (7.8)
Medical Practitioners (Specialists & GPs)	43 (10.8)
Recreational Officer/ Diversional Therapist	20 (5.1)
Other**	51 (12.8)

[#]Not all respondents completed all survey items, hence the number of respondents to each survey item is also included in the table; *Other mainly included individuals who worked across multiple settings;

**Other included Nurse Practitioners/ Clinical Nurse Consultants/ Directors of Nursing (6), Case Managers/ Coordinators (12), and Support Workers and other Managers;

The vast majority were female (354; 89%) and most worked in residential aged care settings (148; 38%) while around one-third (33%) worked in community care settings and almost one-fifth (19%) worked in hospital settings including acute and sub-acute hospital wards – see Figure 2. Registered nurses were the most highly represented occupational group (35%), followed by allied health professionals including physiotherapists, psychologists (22%) while medical practitioners including GPs and medical specialists comprised around 10% of respondents – see Figure 3.





4.1.2 Characteristics of the client population

Individual survey responses to items regarding the characteristics of their clients are presented in Table 2. Most respondents (81%) reported they currently provide care for veterans and almost all reported caring for people with dementia (99.7%). Of those, almost one-half (47%) reported caring for between 20-100 people with dementia – see Figure 4, and the majority (66%) reported seeing their clients with dementia on a very regular basis – more than once a week, indicating they knew their clients very well and were familiar with them and their behaviours and were consequently able to provide accurate information about them – see Figure 5. The majority of respondents (89%) reported that at least some of their clients with dementia were also war veterans, with the most frequently endorsed response showing that a minority of their clients with dementia (1-9%) were also war veterans – see Figure 6. The majority of respondents (93%) also reported that at least some of their clients with dementia were male. Slightly over half (52%) of the respondents reported that most of their clients with dementia were male, while for the remainder, a minority were male - see Figure 7. This question was included as male veterans were more likely to have seen active military service than females (Dunt et al., 2012). Most respondents reported that a percentage of their veteran clients with dementia had seen active military service in a war zone. Of those, nearly one-third (31%) reported that this was true for most of their clients (between 50-100%), while almost one-half (45%) reported that fewer than 50% of their clients with dementia had served in a war zone. Of those, most (30%) reported that a minority of their clients (1-9%) had served in an active war zone. See Figure 8.

Almost half of the respondents (49%) reported that some of their veteran clients with dementia had a prior diagnosis of PTSD and most reported the diagnosis had been made in less than 50% of their clients, although much higher rates (50-100%) were reported by some (13%). The actual rate may be higher as almost one-third of respondents (30%) reported they did not know whether their veteran clients with dementia had a past history of PTSD – see Figure 9.

Table 2: Individual Survey responses - characteristics of the client population

Survey Item	Response - Number (%)
Do you currently care for any veterans? (Total n = 398)	
Yes	321 (80.7)
No	77 (19.4)
How many people with dementia do you care for? (Total n = 293)	
None	1 (0.3)
1-9	70 (23.9)
10-19	60 (20.5)
20-100	137 (46.8)
Don't know	25 (8.5)
How often, on average, do you usually see your clients with dementia? (Total n = 293)	
Less than once a week	67 (22.9)
Once a week	31 (10.6)
More than once a week but less than daily	72 (24.6)
Daily	71 (24.2)
More than once a day	52 (17.7)
Of those with dementia that you care for, approximately what percent (%) are veterans (of any war)? (Total n = 297)	
None	6 (2.0)
1-9%	161 (54.2)
10-24%	60 (20.2)
25-49%	23 (7.7)
50-74%	10 (3.4)
75-100%	11 (3.7)
Don't know	26 (8.8)
Of the veterans with dementia that you care for, approximately what percent (%) are male? (Total n = 237)	
None	7 (2.9)
1-9%	75 (31.6)
10-24%	16 (6.7)
25-49%	15 (6.3)
50-74%	51 (21.5)
75-100%	73 (30.8)
Of the veterans with dementia that you care for, approximately what percent (%) saw active military service in a war zone? (Total n = 242)	
None	13 (5.4)
1-9%	73 (30.2)
10-24%	22 (9.1)

25-49%	16 (6.6)
50-74%	30 (12.4)
75-100%	46 (19.0)
Don't Know	42 (17.4)
Of the veterans with dementia that you care for, approximately what percent (%) have a previous diagnosis of PTSD? (Total n = 241)	
None	50 (20.8)
1-9%	56 (23.2)
10-24%	20 (8.3)
25-49%	12 (5.0)
50-74%	16 (6.6)
75-100%	15 (6.2)
Don't Know	72 (29.9)
Over the past month, have any of the veterans that you care for, appeared to re-live a traumatic military experience? (Total n = 243)	
Yes	69 (28.4)
No	118 (48.6)
Don't know	56 (23.0)
If yes, in how many veterans has this happened? (Total n = 75)	
One	35 (46.7)
Two	20 (26.7)
Three	10 (13.3)
Four	3 (4.0)
Five or more	7 (9.3)
If yes, how often did this occur? (Total n = 118)	
Once only	23 (19.5)
1-2 times	44 (37.3)
3-4 times (i.e. once a week)	28 (23.7)
Daily	15 (12.7)
Several times a day	8 (6.8)

[#]Not all respondents completed all survey items, hence the number of respondents to each survey item is also included in the table);

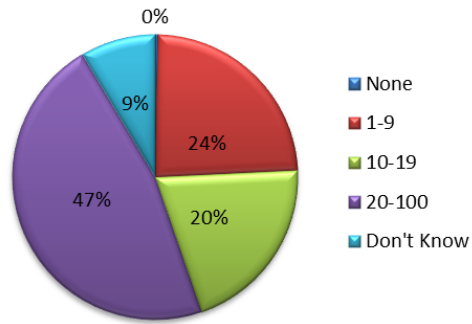


Figure 4. Number of clients with dementia

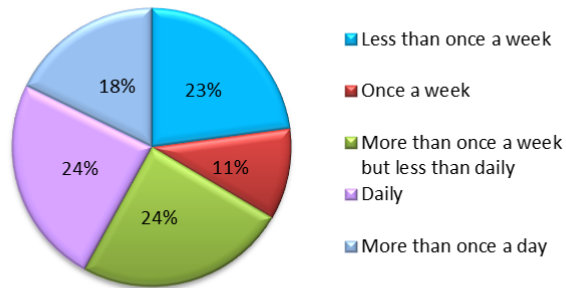


Figure 5. Frequency with which clients with dementia are seen

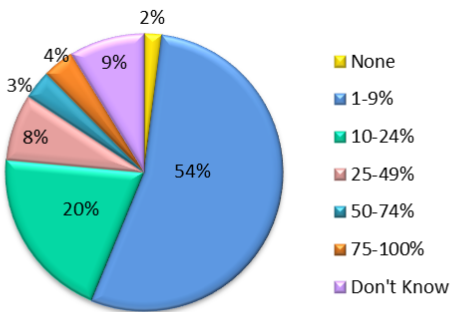


Figure 6. Percent of clients with dementia who are war veterans

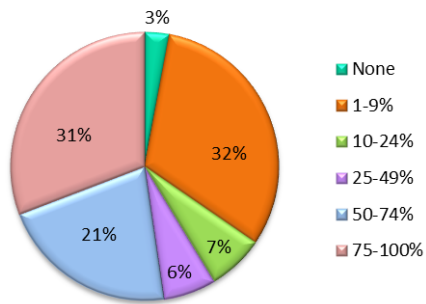


Figure 7. Percent of veterans with dementia who are male

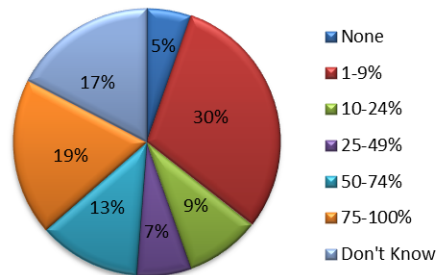


Figure 8. Percent of veterans with dementia who served in a war zone

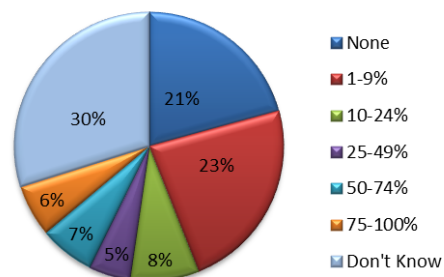


Figure 9. Percent of veterans with dementia AND previous PTSD

4.1.3. Reliving traumatic military experiences by veterans with dementia - frequency and characteristics

Finally, almost one-third of respondents (28%) reported that one or more of their veteran clients with dementia had appeared to relive a traumatic military experience (e.g. diving for cover fearing an air raid attack) over the past month, although the number may be higher as 23% of respondents did not know whether such an event had occurred. Around one-half of respondents (47%) reported this had occurred in only one of the veterans with dementia for whom they cared, although 40% reported this had occurred in two to three veterans. In response to the question regarding the frequency with which such episodes had occurred, the majority of respondents (57%) reported that such an episode had occurred once or twice only, while around 20% reported that such episodes had occurred daily or several times a day over the past month – see Table 2.

Thirty-four respondents described episodes they had personally witnessed while another 32 provided second-hand accounts of episodes that had been described to them by another – see Table 3. In both cases, symptoms of extreme distress, severe anxiety, agitation and fear were the most frequently reported symptoms. It was reported that some veterans with dementia exhibited extreme nervous reactions to sudden, loud noises (e.g. a fire alarm sounding or a car backfiring) which was sometimes thought to be an air raid siren or gun fire. Several would hide or attempt to hide under tables or under the covers for protection from the perceived threat. The veterans were frequently described as being hypervigilant, jumpy and generally afraid, and screaming, crying and yelling was described in seven veterans. Physical aggression was also reported, although to a lesser degree, and this generally appeared to be within the context of experiencing a hallucination or delusion and the veteran was trying to escape or hide themselves or others (e.g. pushing someone in the way of the veterans getting to a safe place or grabbing someone to take them to safety). Nightmares and disturbed sleep were also reported in seven veterans and one respondent described an episode in which a veteran had woken at night and grabbed his wife's throat (with potentially very serious consequences). The manner in which that episode was resolved was not described although another respondent reported that one veteran's son felt unable to calm or reassure his father following such an episode.

Seven respondents provided information about the duration of the episodes they had witnessed, which ranged in duration from 5-10 minutes (1 veteran), to 20-30 minutes (3 veterans), to 2-3 hours (2 veterans), to constant (1 veteran).

Finally, respondents were asked whether, in their experience, there were any differences in BPSD displayed by veterans with dementia and a past history of PTSD in comparison to others with dementia. A majority (n= 79; 66%) reported that veterans with dementia and a past history of PTSD displayed more severe BPSD than others with dementia while 40 respondents (34%) reported they had not observed any differences in BPSD between the two groups. Three respondents reported that others with dementia and a history of non-war related trauma (e.g. abuse, severe accidents) also displayed more serious BPSD than those without such histories. Symptoms specifically mentioned, as being more severe in the group with PTSD included increased agitation, anxiety and fearfulness; verbal and physical aggression; hallucinations and delusions; nightmares and sleep disturbances – see Table 4.

Table 3: Characteristics of relived traumatic military experiences – Individual respondent reports

Description of what the veteran(s) with dementia did, including duration of the episode (Total respondents = 34)	Number of veterans affected
Agitated behavior/ hypervigilance / jumpy/ restless behavior,	12
Hiding under table or in room/ cowering/ trying to hide self or others / ducking for cover,	10
Verbal aggression/ screaming/ yelling (e.g. “can you see the planes?”),	8
Emotional distress/ crying,	7
Physical aggression (e.g. attempting to grab or hit people),	4
Discussing plans for attack or invasion,	3
Reacting fearfully to loud noises,	2
Becoming fearful in small confined spaces,	1
Asking for reassurance that the area is clear,	1
Reacting violently to an Asian staff member,	1
If you did not personally witness the episode(s), but someone who witnessed it described it to you, please describe what you were told (Total respondents = 32)	Number of veterans affected
Nightmares/ trouble sleeping / vivid dreams causing anxiety and distress,	7
Agitation/ ducking for cover (or hiding) in response to loud noise (e.g. fire alarm; traffic noise),	6
Verbal aggression (e.g. yelling, shouting),	4
Agitation/ anxiety/ hypervigilance / fearfulness,	11
Delusions of being in a war zone,	6
Physical aggression – pushing (2 veterans); waking and grabbing wife’s throat (1 veteran),	3
Flashbacks,	1
In your experience, do the BPSD symptoms displayed by veterans with dementia and a prior diagnosis of PTSD differ from those of others with dementia but no diagnosis of PTSD. Please describe what you have observed.	Number of respondents (Total = 119)
Seventy-nine respondents (66%) reported that veterans with dementia and a past history of PTSD displayed more severe BPSD than others with dementia. Symptoms specifically mentioned included:	
Increased agitation, anxiety and fearfulness including heightened fear reactions to loud noises,	29
Verbal and physical aggression,	24
Hallucinations/ delusions / Re-experiencing war-time experiences,	12
More difficult to calm down or reassure,	6
Nightmares / sleep disturbances,	5
Depression,	3

Six respondents reported that veterans with dementia and a history of PTSD were more difficult to calm down or reassure than others with dementia.

Finally, respondents were also asked whether they were able to assist the veterans with dementia to calm down or recover following such an episode, and to describe these interventions. Forty-eight respondents described a range of strategies they found useful in this situation. Reassurance that the war was over and that the veteran was safe and speaking in a very calm, quiet voice was the most frequently reported strategy. This was followed by distraction and re-directing the individual's attention elsewhere by changing the topic of conversation or environment (e.g. going outside or somewhere quiet). All of the reported strategies are listed in Table 4.

Table 4: Strategies to assist veterans to calm down/ recover following a reliving experience

Useful strategies	Number of respondents (Total = 48)
Most respondents reported the following strategies were useful in assisting the resident to calm down within a reasonable amount of time:	
Reassurance (e.g. that the war is over and that the veteran is safe), speaking in a calm, quiet voice,	23
Use of distraction and re-direction / change of topic of conversation or environment (e.g. moving to a quiet area),	13
Reorientation to person, time and place,	5
Use of medication (antidepressants, mood stabilizers),	5
Listen to the resident's concerns and acknowledge his/ her concerns (e.g. 'that must have been terrible'),	5
Enter into veteran's world – acknowledge the veteran is doing an excellent job looking after his men; the veterans concerns would be passed onto his Commanding Officer,	4
Allow resident to walk away/ hide,	1
Hospitalisation,	1
Two respondents listed the following actions as useful preventive strategies:	
Roster Non-Asian staff, Never touch the person unexpectedly,	2
Always approach the resident within their field of vision,	
Explain what you are going to get the resident to do or want them to do and provide any instructions step by step,	
Remove potential weapons,	
Regular massage and physical exercise,	

4.2 Responses from Managerial Staff/ Senior staff working in residential aged care facilities

4.2.1 Demographic characteristics of Managers/ Senior staff

Responses to the survey were received from 197 managerial and senior administrative staff working in RACFs and their demographic characteristics are displayed in Table 5. Each Australian state and territory was represented although most responses came from Queensland, NSW and Victoria which were approximately equally represented (24% each) – see Figure 10. As was the case with the individual survey respondents, the ACT and the Northern Territory had the lowest levels of representation (2% and 1% respectively) and it was not possible to accurately calculate a response rate as the survey was distributed widely through multiple avenues and the total number of managers and senior RACF staff who received or who saw the survey is not known. Nevertheless, the response rate is low, considering the DSS contact database of managers and senior RACF staff included around 5,000 names.

Slightly over half (56%) of the respondents were Managers of Residential Care Services while another 19% were Clinical Care Managers with CEOs and other managers and administrators making up the remainder. The size of the facilities represented ranged in size from very small (19 places in total) to very large (1,500 places) that provided care for few residents with high care needs (one facility had only one place designated as high care) to facilities that cared solely for residents with high care needs (the manager of the largest facility reported that 100% of places were high care). The overwhelming majority (93%) indicated their facility currently cares for veterans.

4.2.2 Characteristics of the residential aged care population

All managers/ senior staff reported that all facilities cared for some residents with a diagnosis of dementia with the majority (70%) reporting that between one-quarter to three-quarters of residents had such a diagnosis – see Table 6 and Figure 11. Most respondents (87%) indicated that, of their residents with dementia, a minority (between 1-19%) were veterans – see Table 6 and Figure 12; and most (55%) reported that a minority of the veterans with dementia living in their facility were male (0-9%) – see Table 6 and Figure 13.

The results also showed that the numbers of veterans with dementia who saw active military service in a war zone ranged from none to 100% with the most frequently endorsed response being 1-9% of veterans (41%) – see Table 6 and Figure 14. Results also indicated that approximately half of the veterans with dementia (49%) did not have a past history of PTSD and that a minority had this diagnosis (27% indicated the diagnosis occurred in 1-9% of veterans with dementia), while PTSD status was unknown by approximately 18% of respondents – See Table 6 and Figure 15.

Table 5: Demographic characteristics of managers/ senior staff

Survey Item	Response Number (%)
State/ Territory where respondent works (Total n = 196) [#]	47 (24.0)
Queensland	48 (24.5)
New South Wales	47 (24.0)
Victoria	15 (7.6)
Western Australia	24 (12.3)
South Australia	12 (6.1)
Tasmania	2 (1.0)
ACT	1 (0.5)
Northern Territory	
Current role in the organization (Total n = 196)	
Chief Executive Officer	13 (6.8)
Director/Manager of Research	5 (2.6)
Senior Administrator	9 (4.7)
Research Ethics Officer/Manager	2 (1.1)
Manager of Residential Care Services	108 (56.3)
Clinical Care Manager	37 (19.3)
Other*	18 (9.4)
Size of the facility and number of residential high care places (Total n = 189)	
Number of residential places; Range, (Average)	19 - 1,500 (130)
Number HIGH care places; Range (Average)	1 - 1,500 (97)

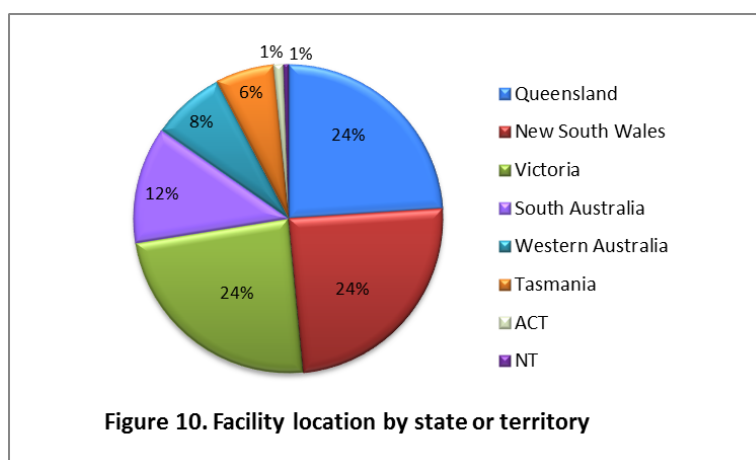


Table 6: Survey responses by Managers/ senior staff - characteristics of the client population

Survey Item	Response – Number (%)
What is the approximate percent (%) of residents with a medical diagnosis of dementia? (Total n = 166)	
None	0 (0)
1-9%	9 (5.4)
10-24%	22 (13.3)
25-49%	55 (33.1)
50-74%	60 (36.2)
75-100%	20 (12.1)
Of the residents with dementia in your facility, approximately what percent (%) are veterans? (Total n = 168)	
None	3 (1.8)
1-9%	94 (55.9)
10-19%	52 (30.9)
20-49%	9 (5.4)
50-74%	2 (1.2)
75-100%	1 (0.6)
Don't know	7 (4.2)
Of the veterans with dementia in your facility, what percent (%) are male? (Total n = 143)	
None	14 (9.8)
1-9%	64 (44.8)
10-19%	17 (11.9)
20-49%	8 (5.6)
50-74%	17 (11.9)
75-100%	23 (16.1)
Of the veterans with dementia in your facility, what percent (%) saw active military service? (Total n = 142)	
None	22 (15.5)
1-9%	58 (40.9)
10-19%	15 (10.6)
20-49%	6 (4.2)
50-74%	12 (8.5)
75-100%	14 (9.9)
Don't know	15 (10.6)
Of the veterans with dementia in your facility, what percent have a previous diagnosis of Post-Traumatic Stress Disorder (PTSD)? (Total n = 140)	
None	69 (49.3)
1-9%	38 (27.1)
10-19%	2 (1.4)
20-49%	3 (2.1)

50-74%	2 (1.4)
75-100%	1 (0.7)
Don't know	25 (17.9)
Over the past month, have any of the veterans with dementia in your facility appeared to relive a traumatic military experience (for example, diving for cover fearing an air attack)? (Total n = 143)	
Yes	24 (16.8)
No	105 (73.4)
Don't Know	14 (9.8)
If yes, in how many veterans has this happened? (Total n = 28)	
One	17 (60.7)
Two	8 (28.6)
Three	3 (10.7)
Four	0
Five or more	0
If yes, how often did this occur? (Total n = 25)	
Once only	7 (18.4)
1-2 times	10 (26.3)
3-4 times (i.e. once a week)	15 (39.5)
Daily	3 (7.9)
Several times a day	3 (7.9)
Were staff able to assist the veteran (s) to calm down or recover? (Total n = 31)	
Yes	23 (74.2)
No	4 (12.9)
Don't know	4 (12.9)

[#]Not all respondents completed all survey items, hence the number of respondents to each survey item is also included in the table);

^{*}Other included a variety of other managerial positions including Director of Nursing, Assistant Manager, Team Leader, Quality Manager, etc.

4.2.3. Reliving traumatic military experiences by veterans with dementia - frequency and characteristics

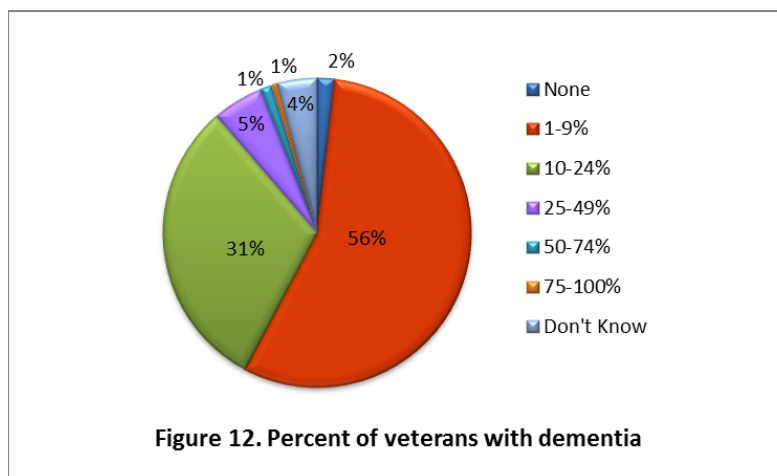
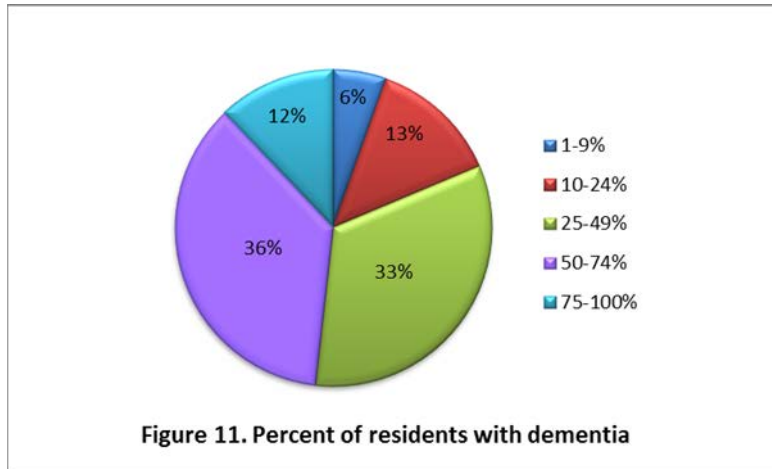
A minority of managers/ senior staff (16%) reported that some of their resident veterans with dementia had appeared to relive a traumatic military experience over the past month. Such an event was reported to have occurred in one resident only by the majority of respondents (61%), although around forty percent indicated that two to three residents had experienced such an episode. Respondents reported, that, in most instances (74%), staff were able to assist the resident to calm down or recover following such an episode – see Table 6.

Twenty-four respondents provided descriptions of such episodes and like the descriptions provided by individual survey respondents, symptoms of agitation, anxiety and fear were prominent. For example, veterans constantly looking over one's shoulder, hiding under the bed or elsewhere, and jumping in response to loud, unexpected noises were reported by nine respondents – see Table 7. Delusions and hallucinations about the war or reliving events that occurred during the war, were, however, the most frequently reported symptom by managers/ senior staff (10 respondents), followed by physical and verbal aggression. Instances of physical aggression included 'attempting to defend oneself with a bread knife' or pushing others out of the way when attempting to hide and had the potential for serious consequences (although no such outcomes were reported). Nine respondents provided information regarding the duration of such episodes. Most episodes were reported to last from around 5-10 minutes to an hour (7 veterans) while other residents experienced episodes lasting from several hours (1 veteran), to 1-2 days (1 veteran), while several residents were reported to live in constant fear and agitation.

Twenty-one respondents described a number of effective interventions that staff had implemented to calm the resident following such an episode. While it was reported that such interventions were effective within a reasonable amount of time, the specific amount of time taken was not reported. As for the individual survey respondents, the most frequently reported strategy reported by managers and senior staff was reassuring the veteran that the war was over and that they were safe as well as talking calmly and quietly. Distracting the distressed veteran by taking him for a walk or to a quiet location, reorienting the veteran to time and place and medication were also reported, while two respondents reported that the removal of male or non-Caucasian staff was occasionally required – see Table 7.

Finally, a majority of respondents (n = 52; 72%), responded in the affirmative to the question regarding whether they considered there were differences in BPSD by veterans with dementia and a past history of PTSD in comparison to others with dementia, and reported that BPSD was more severe in those with a history of PTSD and they are more difficult to calm or settle. By comparison, 20 respondents (28%) reported that they had not observed any differences between the two groups. Delusions or hallucinations as well as reliving war experiences were the most frequently reported symptom, followed by increased verbal and physical aggression and increased agitation and anxiety. In addition, fearfulness or suspiciousness of Non-Caucasian staff (particularly staff of Asian appearance in the case of older veterans), and reacting negatively to these staff members was mentioned by seven respondents with

important implications for managers and administrators who are responsible for appointing and rostering staff.



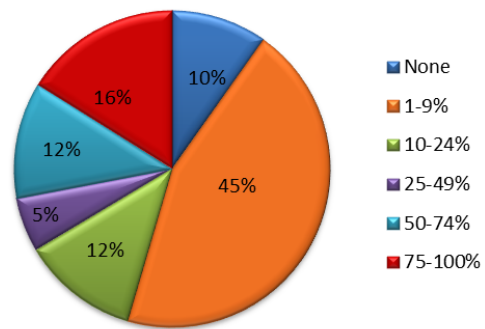


Figure 13. Percent of male veterans with dementia

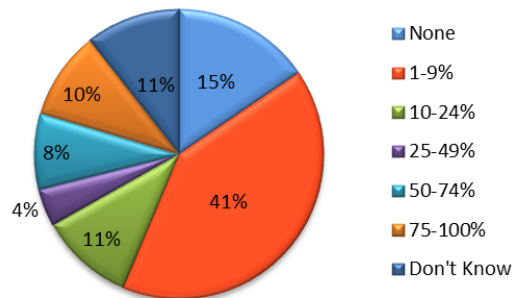


Figure 14. Percent of veterans who saw active military service

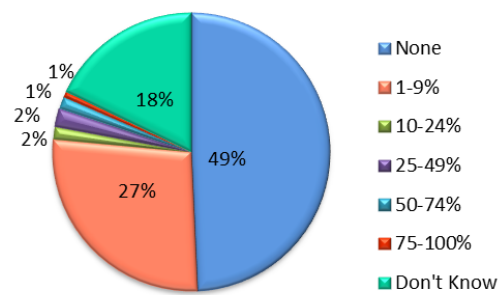


Figure 15. Percent of veterans with dementia AND previous PTSD

Table 7. Characteristics of relived traumatic military experiences – Managerial/ Senior staff reports

Description of what the veteran(s) with dementia did, including duration of the episode	Number of respondents (Total = 24)
Delusions (e.g. about food being poisoned) or hallucinations about war events/ Reliving a war experience,	10
Physical aggression (e.g. pushing staff in an attempt to get away or attempting to defend self with a weapon e.g. bread knife; aggression towards Asian staff),	7
Agitation/ displaying fearful behavior (e.g. constantly looking over shoulder),	6
Verbal aggression including yelling out and abuse,	4
Hiding under the bed or under bed-covers,	2
Sleep disturbances,	2
Jumping in response to loud, unexpected noises,	1
Staff interventions and effectiveness	Number of respondents (Total = 21)
Reassurance that the war was over and the resident was safe – talking calmly and quietly,	9
Distraction, e.g. by taking the resident for a walk or to a different environment,	8
Reorientation to time and place,	3
Medication,	4
Removing male or non-Caucasian staff,	2
Involving the Dementia Behaviour Management Advisory Service (DBMAS),	1
In your experience, do the BPSD symptoms displayed by veterans with dementia and a prior diagnosis of PTSD differ from those of others with dementia but no diagnosis of PTSD. Please describe	Number of respondents (Total = 72)
Fifty-two respondents (72%) reported that veterans with dementia and a past history of PTSD displayed more severe BPSD than other people with dementia. Symptoms specifically mentioned included:	
Delusions/ hallucinations / Reliving war time experiences,	14
Increased verbal and physical aggression,	11
Increased agitation, anxiety and fear,	9
Fearful or suspicious or reacting negatively towards non-Caucasian staff (e.g. Asians in the case of older veterans) ,	7
Veterans with dementia and PTSD are more difficult to settle or manage ,	5
Heightened reactions to sudden, loud noises (e.g. may duck for cover),	2
Increased anger, hostility,	2
More withdrawn and depressed,	1

4.3 Survey Response Rate

Overall, almost 600 surveys were returned (401 individuals surveys and 197 surveys by managers and senior RACF staff), and while it was not possible to calculate an accurate response rate as the survey was distributed widely through multiple avenues, and the total number of people who received or who saw the survey is not known, a rough estimate is possible. Based on an estimated 7,000 surveys emailed, a response of 600 yields a response rate of around 8.6%, representing a low rate of return. Low response rates by healthcare professionals to online surveys has been identified as a shortcoming and rates as low as 9% have previously been reported (Braithwaite et al., 2003; Cho et al., 2013). Furthermore, response rates have fallen in association with the recency of the survey – a finding that has been attributed to the increased volume of online surveys and other email traffic in more recent years (Cho et al., 2013). While the low response rate means the results may not be generalizable across all healthcare settings that provide care for older people with dementia, important data has been provided regarding BPSD in veterans with dementia that has been interpreted conservatively.

4.4 Data from Commonwealth Agencies

4.4.1 Australian Institute of Health and Welfare (AIHW) Data

In response to our data request, the AIHW National Aged Care Data Clearinghouse provided ACFI data in relation to verbal (verbally disruptive behaviour that is severe enough to require staff intervention), and physical behaviour (e.g. physically disruptive or socially inappropriate behaviour that is severe enough to require staff intervention), problems displayed by permanent RACF residents as at June 2010, 2011 and 2012. While the data provided by the AIHW was categorised according to gender, dementia status and DVA pension status, they were unable to provide any information regarding PTSD status. Furthermore, not everyone in receipt of a DVA pension are veterans (spouses and other dependants are eligible for some DVA pensions) and it is not known how many saw active military service. Hence, the data cannot be used to make any conclusions regarding BPSD in veterans with a history of PTSD and were not included in this report.

4.4.2 Australian Government Department of Social Services (DSS) Data

The DSS provided data in relation to the numbers of people assessed by an ACAT assessor by gender, dementia diagnosis and DVA status for 2009-2013. Once again, however, they were unable to provide any data regarding prior PTSD diagnosis or active military service, hence the data cannot be used to draw any conclusion regarding the influence of PTSD on the expression of BPSD in veterans with dementia, and has not been included in this report.

Section 5. Summary and Discussion

5.1 Summary of Findings

Almost six hundred surveys were returned from individual healthcare workers who care for older people with dementia and managers and senior administrative RACF staff. Four hundred and one surveys were returned from individuals working across a range of healthcare settings including the community, hospital and RACFs while 197 surveys were received from managers and senior administrative RACF staff. The vast majority of individual respondents were female (89%), most worked in RACFs (38%), and registered nurses was the most highly represented occupational group (35%). Survey results indicate that the individual healthcare providers who completed the survey knew their clients well – the majority reported seeing their clients with dementia very regularly (66% reported seeing such clients more than once a week) and were consequently able to provide accurate information about them. A majority of respondents (75%) to Survey 2 (Managers/ Senior staff survey) were RACF Managers or Clinical Care Managers representing RACFs ranging in size from very small (19 places) to very large (1,500 places).

While survey respondents represented all Australian States and Territories, the estimated response rate was low (around 8.6%) meaning the survey results may not be generalizable across all healthcare settings that provide care for older people with dementia. Accordingly, the data have been interpreted conservatively and in spite of the low response rate, the data provide important new information regarding an issue that has not previously been well investigated, and that appears to be a significant issue for a minority of older veterans with dementia and those who care for them.

Almost all survey respondents reported caring for older people with dementia and the vast majority of both individual respondents and managers/ senior RACF staff reported that either they, or the RACF wherein they worked, cared for veterans (81%, 93% respectively). Most respondents also indicated that a minority of their clients with dementia (less than 25%) were also veterans, of whom a minority (less than 25% was the most frequently response) were reported to have seen active military service, although this was unknown in a substantial number of cases. Approximately half the respondents further reported that a minority of their veteran clients with dementia had a past history of PTSD (generally between 1-9%), while almost 50% of individual respondents and 21% of managers/senior RACF staff reported that the veteran with dementia for whom they cared, did not have such a history. PTSD status was reported to be unknown by a substantial number of respondents - 30% of individual respondents and 18% of managers or senior RACF staff, allowing one to speculate that perhaps symptoms characteristic of PTSD (hypervigilance, extreme agitation and anxiety, reliving experiences) may not been a significant issue for those clients.

Most respondents (66% of individuals and 72% of managers/ senior RACF staff) reported that veterans with dementia and PTSD had more severe BPSD and were more difficult to calm and settle than clients with dementia but who did not have PTSD. Symptoms reported to be more severe in those with a history of PTSD included increased agitation, anxiety and fearfulness, delusions, hallucinations and

reliving experiences, increased verbal and physical aggression as well as nightmares and sleep disturbances.

A minority of respondents (28% of individuals and 17% of managerial/ senior RACF staff) reported that some of their veteran clients with dementia appeared to have relived a traumatic military experience over the past month. This usually occurred in one or two veterans only, although RACF managers and senior staff reported that as many as five or more veterans had experienced such episodes. The episodes had generally occurred once or twice only, although there were reports of daily or more frequent occurrences in a minority of veterans. In most instances, staff were able to reassure or calm the veteran following such an episode.

Descriptions of reliving episodes by individuals and manager/ senior staff were very similar with symptoms of severe anxiety, agitation and fearfulness being paramount. It was reported that some veterans with dementia exhibited extreme fear reactions to loud, unexpected noises, perhaps thinking the noise was gun fire or an air raid siren, and diving for cover under a table or bed. Some were reported to be very jumpy and to exhibit hypervigilant behavior, for example, constantly looking over their shoulder for some perceived threat while crying, screaming and yelling were also common. Reports of hallucinations and delusions were frequently reported with several veterans believing they were in a war zone or under attack. Aggression, both verbal and physical, was also reported, although to a lesser degree, and physical aggression generally appeared to result from a delusional belief that the veteran was about to be attacked and pushed someone in an attempt to get away, or grabbed another in an attempt to hide them. Two instances of aggressive behavior with potentially very serious consequences were reported – the first was a report of a veteran trying to defend himself with a bread knife, while the second reported a veteran waking suddenly in the night and grabbing his wife's throat (no serious outcomes were reported). Reacting negatively, suspiciously or aggressively towards Non-Caucasian staff (particularly staff of Asian appearance in the case of older veterans) was also reported by several respondents as an issue, and awareness of this when rostering staff was reported by one respondent as a preventive strategy. While it appears this issue does not concern large numbers of veterans with dementia, it is important for healthcare providers to be aware of this as a potential issue that may need to be addressed.

Most reliving episodes were generally of short duration with most lasting from 5-10 minutes to 1-2 hours, although episodes could last up to a couple of days while a small minority were reported to live in constant fear and agitation. Both individuals and managers/ senior RACF staff reported using a range of strategies that were effective in assisting the veteran to calm down following such an episode. The most frequently reported strategies were providing reassurance that the war was over and that they were safe, talking calmly and quietly or distracting the veterans by taking him to another room or quiet place or changing the topic of conversation.

5.2 Discussion

Results of this national survey show that a substantial minority of older people with dementia who receive care, either in the community, hospital or in a residential care setting, are war veterans. Of those, a substantial minority had seen active military service in a war zone and a substantial minority had a past history of PTSD. Although our results do not reveal whether the veterans who had seen active military service were also those with PTSD, this seems likely. Most survey respondents reported that BPSD is more severe in veterans with dementia who have a history of PTSD compared to people with dementia but no PTSD. Symptoms most frequently reported included increased agitation, anxiety, fearfulness including sometimes extreme reactions to sudden loud noises, delusions and hallucinations, reliving traumatic military experiences and verbal and physical aggression which very occasionally had the potential for serious consequences. The most frequently reported management strategies were psychosocial interventions recommended for managing BPSD, generally (DCRC-ABC, University of NSW, 2012) and included providing reassurance, talking calming and quietly or distraction and ensuring noise was minimized.

Our findings are consistent with those of another Australian study undertaken by Dunt and colleagues (2012) who also investigated the relationship between PTSD and dementia in veterans. They collected data from the carers and case managers of 40 male veterans and 96 male non-veterans living in the community and their findings indicated that BPSD symptoms were significantly higher in veterans with PTSD than in non-veterans, and that BPSD was more severe in veterans with dementia and past PTSD ($n=7$) compared to those without PTSD ($n=17$). As we found, Dunt and colleagues also found that the following symptoms were more severe in veterans with dementia and PTSD: verbal and physical aggression, delusions, hallucinations, nervousness, anxiety and sleep disturbances. Our findings, together with those of Dunt and colleagues add to a small but growing body of evidence that indicates that BPSD appears to be a significant concern for a minority of veterans with dementia and those who care for them.

5.3 Study Limitations

An important study limitation is the low response rate, potentially limiting the generalizability of the findings as it is not known how representative the findings are. Nevertheless, almost 600 responses from across a range of Australian healthcare settings were received and this is the largest study, to date, that has examined the relationship (or lack thereof) between PTSD and the expression of BPSD in veterans with dementia. The individual survey respondents reported seeing their clients very regularly and as far as we were able to ascertain, the respondents were able to provide accurate data about their clients. Furthermore, the similarity of the descriptions of the BPSD displayed by the individual survey respondents and Managers/ Senior RACF staff enhances the credibility of the findings.

The possibility of response bias, however, cannot be overlooked and it may be that those who have encountered veterans with significant BPSD were more motivated to respond to the survey than others who may have cared for veterans but who have not exhibited significant BPSD. In addition, a substantial

number of respondents did not know the PTSD status of their veteran clients with dementia nor whether they had seen active military service. While this suggests PTSD may not have been an issue for those clients, it could also be that the client may have had PTSD previously which may have resolved or it may not have had an impact on their dementia.

Nevertheless, the survey findings indicate that the expression of BPSD appears to be more severe in some veterans with dementia and a past history of PTSD, and are particularly distressing for a minority.

5.4 Conclusions

It is concluded that BPSD appears to be more severe in a significant minority of veterans with dementia and a past history of PTSD. While this appears to be an important issue for a minority of older veterans with dementia and their carers, the results show that the symptoms are extremely distressing for those affected and are challenging to manage.

On the basis of the survey findings, the following recommendations have been made:

5.5 Recommendations

1. It is recommended that all healthcare personnel who care for older people with dementia as well as facility managers and administrators be made aware of the likelihood that some of their clients will be war veterans who may have witnessed traumatic events during their war service which may influence the expression of BPSD. Similarly, PTSD secondary to other traumatic experiences (non-war related) may also influence the expression of BPSD in people with dementia and care and facility staff should also be cognizant of this possibility. Awareness of this issue is particularly important for RACF managers and administrators who are responsible for staff rosters as well as for non-Caucasian staff, as a minority of older veterans with dementia react negatively, suspiciously or aggressively towards Non-Caucasian staff (particularly those of Asian appearance in the case of older veterans). Accordingly, a sensitive and appropriate management strategy is required.
2. Given that BPSD appears to be a significant issue for a minority of veterans with PTSD only, it is unlikely that the development of a comprehensive stand-alone educational package for healthcare staff is required. Nevertheless, the inclusion of a module specifically addressing serious BPSD for war veterans and other trauma survivors (including potential preventive and management strategies) within existing resources (e.g. Behaviour Management: A Guide to Good Practice. Managing Behavioural and Psychological Symptoms of Dementia. DCRC-ABC, University of New South Wales; 2012) is likely to be useful. Such a resource should include details of the symptoms displayed and potential triggers as well as appropriate and effective management strategies, particularly as physical aggression has the potential for serious consequences.

3. As the research evidence regarding the relationship between the expression of BPSD and PTSD in veterans is limited, and given this may become an issue of considerable magnitude in the foreseeable future as the number of older veterans increases, it is recommended that further research be undertaken to further clarify any such relationship. The addition of questions regarding veterans' prior PTSD diagnosis and active military service to existing data collection tools (e.g. the Aged Care Funding Instrument) is likely to be a cost-effective method of obtaining the necessary data to explore this question. Issues particularly relevant for the DTSCs include the identification of the most effective and appropriate management strategies for BPSD in this population. In addition, the usefulness of environmental and other interventions to prevent the escalation of BPSD that is both distressing for the veteran and challenging for staff to manage, ought to be explored.

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APPENDIX A. Survey 1 – Individual Healthcare staff

A survey of dementia in veterans and non-veterans.

PARTICIPANT INFORMATION

QUT Ethics Approval Number 1400000428

RESEARCH TEAM

Principal Researcher: Professor Elizabeth Beattie, Professor,
Associate Researcher: Dr Catherine Travers, Project Coordinator,
Qld Dementia Training Study Centre (DTSC), School of Nursing, Faculty of Health, Queensland
University of Technology (QUT)

DESCRIPTION

This project is being undertaken by Qld DTSC. The purpose of this project is to better understand the symptoms of dementia displayed by veterans and non-veterans and to determine whether there are any important differences in the symptoms displayed by the two groups. We also hope to identify what issues this creates for carers and determine whether there is a need to develop additional training resources to better assist carers in their caring role.

PARTICIPATION

You are invited to participate in this project because your name is listed on the Queensland Dementia Training Study Centre (Qld DTSC) contact database or because it has been forwarded by a colleague on that list through other professional networks. Participation will involve completing an anonymous 18 item online survey that will take approximately 5-10 minutes of your time. Examples of questions include:

What is the approximate percentage of residents with a medical diagnosis of dementia? and
Of the veterans with dementia in your facility, what percent have a previous diagnosis of Post-Traumatic Stress Disorder (PTSD)?

Your participation in this project is entirely voluntary. If you agree to participate you do not have to complete any question(s) you are uncomfortable answering. Your decision to participate or not participate will in no way impact upon your current or future relationship with QUT or Qld DTSC. If you agree to participate you can withdraw from the project without comment or penalty. However as the questionnaire is anonymous once it has been submitted it will not be possible to withdraw.

EXPECTED BENEFITS

It is expected that this project will not directly benefit you. However, it may benefit people with dementia and those who care for them.

RISKS

There are no risks beyond normal day-to-day living associated with your participation in this project.

PRIVACY AND CONFIDENTIALITY

All comments and responses are anonymous and will be treated confidentially unless required by law. The names of individual persons are not required in any of the responses. Any data collected as part of this project will be stored securely as per QUT's Management of research data policy. Please note that non-identifiable data collected in this project may be used as comparative data in future projects or stored on an open access database for secondary analysis.

CONSENT TO PARTICIPATE

Submitting the completed online questionnaire is accepted as an indication of your consent to participate in this project.

QUESTIONS / FURTHER INFORMATION ABOUT THE PROJECT

If you have any questions or require further information please contact the research team member below:

Dr Catherine Travers - Project Coordinator - QLD DTSC - QUT
Telephone: 07 3138 3884; Email: catherine.travers@qut.edu.au

CONCERNS / COMPLAINTS REGARDING THE CONDUCT OF THE RESEARCH PROJECT

QUT is committed to research integrity and the ethical conduct of research projects. However, if you do have any concerns or complaints about the ethical conduct of the project you may contact the QUT Research Ethics Unit on [+61 7] 3138 5123 or email ethicscontact@qut.edu.au. The QUT Research Ethics Unit is not connected with the research project and can facilitate a resolution to your concern in an impartial manner.

Thank you for helping with this research project.

Please complete this survey if you provide direct care to older people with dementia, whether in the community or residential care setting.

1. In which state or territory do you work?

New South Wales

Queensland

Victoria

South Australia

Western Australia

Tasmania

Australian Capital Territory

Northern Territory

2. Which of the following best describes your work setting?

Residential Care
Community Care
Other
If other, Please describe

.....

3. This survey is intended for healthcare workers who care for older people.
Which of the following best describes your occupation?

Registered Nurse
Enrolled Nurse
Personal Care Assistant
Allied Health Professional
Allied Health Assistant
Other
If other, Please describe

.....

4. What is your gender?

Male
Female

5. Do you currently provide care for any VETERANS? MALE VETERANS are those with white, gold and orange cards OR other Department of Veterans Affairs (DVA) entitlements while FEMALE VETERANS are those with white or orange cards.

Yes
No

6. How many people with DEMENTIA do you provide care for?

None
1-9
10-19
20-100
Don't Know

7. How often, on average, do you usually see your clients with dementia?

Less than once a week

Once a week

More than once a week but less than daily

Daily

More than once a day

8. Of those with dementia that you care for, approximately what percent (%) are veterans (of any war)?

None

1-9%

10-24%

25-49%

50-74%

75-100%

Don't know

9. Of the VETERANS with DEMENTIA that you care for, approximately what percent (%) are MALE?

None

1-9%

10-24%

25-49%

50-74%

75-100%

10. Of the VETERANS with DEMENTIA that you care for, approximately what percent (%) saw active military service in a war zone?

None

1-9%

10-24%

25-49%

50-74%

75-100%

Don't Know

11. Of the VETERANS with DEMENTIA that you care for, approximately what percent have a previous diagnosis of Post-Traumatic Stress Disorder (PTSD)?

- None
- 1-9%
- 10-24%
- 25-49%
- 50-74%
- 75-100%
- Don't Know

12. Over the past month, have any of the VETERANS with DEMENTIA that you care for, appeared to relive a traumatic military experience (for example, diving for cover fearing an air attack)?

- Yes
- No
- Don't Know

13. If yes, in how many veterans has this happened?

- One
- Two
- Three
- Four
- Five or more

14. If yes, how often did this occur? Please select one response for each veteran (up to a maximum of 5) who displayed this behaviour.

Frequency	Veteran 1	Veteran 2	Veteran 3	Veteran 4	Veteran 5
Once only					
1-2 times					
3-4 times (i.e. approximately once a week)					
Daily					
Several times a day					

15. Did you personally witness the event(s)? If Yes, please describe what the veteran with dementia did, including how long the episode(s) lasted. If No, please proceed to the next question.

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16. If you did not personally witness the event(s), but someone who witnessed it, described it to you, please describe what you were told.

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17. When these episodes occur, are you able to do anything to assist the person to calm down or recover? If yes, please describe what you do and what effect this has on the person(s) with dementia.

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18. In your experience, do the Behavioural and Psychological Symptoms (BPSD) of dementia (e.g. verbal or physical aggression, hallucinations, anxiety, apathy, wandering etc.) displayed by VETERANS WITH DEMENTIA AND a PREVIOUS DIAGNOSIS OF PTSD differ from those displayed by other people with dementia (i.e. VETERANS WITHOUT PTSD or non-veterans). Please describe what you have observed.

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Appendix B. Survey 2 – Survey for Managers and Senior RACF staff

A survey of dementia in veterans and non-veterans.

PARTICIPANT INFORMATION

QUT Ethics Approval Number 1400000428

RESEARCH TEAM

Principal Researcher: Professor Elizabeth Beattie, Professor,
Associate Researcher: Dr Catherine Travers, Project Coordinator,
Qld Dementia Training Study Centre (DTSC), School of Nursing, Faculty of Health, Queensland
University of Technology (QUT)

DESCRIPTION

This project is being undertaken by Qld DTSC. The purpose of this project is to better understand the symptoms of dementia displayed by veterans and non-veterans and to determine whether there are any important differences in the symptoms displayed by the two groups. We also hope to identify what issues this creates for carers and determine whether there is a need to develop additional training resources to better assist carers in their caring role.

PARTICIPATION

You are invited to participate in this project because your name is listed on the Queensland Dementia Training Study Centre (Qld DTSC) contact database or because it has been forwarded by a colleague on that list through other professional networks. Participation will involve completing an anonymous 16 item online survey that will take approximately 5-10 minutes of your time. Questions will include:

What is the approximate percentage of residents with a medical diagnosis of dementia? and
Of the veterans with dementia in your facility, what percent have a previous diagnosis of Post-Traumatic Stress Disorder (PTSD)?

Your participation in this project is entirely voluntary. If you agree to participate you do not have to complete any question(s) you are uncomfortable answering. Your decision to participate or not participate will in no way impact upon your current or future relationship with QUT or Qld DTSC. If you agree to participate you can withdraw from the project without comment or penalty. However as the questionnaire is anonymous once it has been submitted it will not be possible to withdraw.

EXPECTED BENEFITS

It is expected that this project will not directly benefit you. However, it may benefit people with dementia and those who care for them.

RISKS

There are no risks beyond normal day-to-day living associated with your participation in this project.

PRIVACY AND CONFIDENTIALITY

All comments and responses are anonymous and will be treated confidentially unless required by law. The names of individual persons are not required in any of the responses. Any data collected as part of this project will be stored securely as per QUT's Management of research data policy. Please note that non-identifiable data collected in this project may be used as comparative data in future projects or stored on an open access database for secondary analysis.

CONSENT TO PARTICIPATE

Submitting the completed online questionnaire is accepted as an indication of your consent to participate in this project.

QUESTIONS / FURTHER INFORMATION ABOUT THE PROJECT

If you have any questions or require further information please contact the research team member below:

Dr Catherine Travers - Project Coordinator - QLD DTSC - QUT
Telephone: 07 3138 3884; Email: catherine.travers@qut.edu.au

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Thank you for helping with this research project.

This survey is intended for senior staff working in Residential Aged Care Facilities.

1. Which of the following best describes your current role within your organisation?

Chief Executive Officer
Director/Manager of Research
Senior Administrator
Research Ethics Officer/Manager
Manager of Residential Care Services
Clinical Care Manager
Other
If Other, Please describe

-
2. In which state or territory do you work?

New South Wales
Queensland
Victoria
South Australia
Western Australia
Tasmania
Australian Capital Territory
Northern Territory

3. What is the total number of permanent residential places provided by your facility and what number of these are classified as residential high care?

Number of permanent residential places (Total)
Number of permanent HIGH care places

4. Do you currently have any VETERANS in your service? MALE VETERANS are those with white, gold and orange cards OR other Department of Veterans Affairs (DVA) entitlements while FEMALE VETERANS are those with white or orange cards.

Yes
No

5. What is the approximate percent (%) of residents with a medical diagnosis of DEMENTIA? Please pick one of the answers below.

None
1-9%
10-24%
25-49%
50-74%
75-100%

6. Of the residents with DEMENTIA in your facility, approximately what percent (%) are VETERANS?

None

1-9%
10-24%
25-49%
50-74%
75-100%
Don't know

7. Of the VETERANS with DEMENTIA in your facility, approximately what percent (%) are MALE?

None
1-9%
10-24%
25-49%
50-74%
75-100%

8. Of the VETERANS with DEMENTIA in your facility, approximately what percent (%) saw active military service in a war zone?

None
1-9%
10-24%
25-49%
50-74%
75-100%
Don't Know

9. Of the VETERANS with DEMENTIA in your facility, approximately what percent have a previous diagnosis of Post-Traumatic Stress Disorder (PTSD)?

None
1-9%
10-24%
25-49%
50-74%
75-100%
Don't Know

10. Over the past month, have any of the VETERANS with DEMENTIA in your facility appeared to relive a traumatic military experience (for example, diving for cover fearing an air attack)?

Yes
No
Don't Know

11. If yes, in how many veterans has this happened?

One
Two
Three
Four
Five or more

12. If yes, how often did this occur? Please select one response for each veteran (up to a maximum of 5) who displayed this behaviour.

Frequency	Veteran 1	Veteran 2	Veteran 3	Veteran 4	Veteran 5
Once only					
1-2 times					
3-4 times (i.e. approximately once a week)					
Daily					
Several times a day					

13. Please describe what the veteran(s) with dementia did, including how long the episode(s) lasted.

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14. Were staff able to assist the veteran(s) to calm down or recover?

Yes
No
Don't Know

15. If yes, please describe what staff did and what effect this had on the veteran(s).

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16. In your experience, do the behavioural and psychological symptoms (BPSD) displayed by VETERANS WITH DEMENTIA AND A PREVIOUS DIAGNOSIS OF PTSD differ from those of other people with dementia (i.e. VETERANS WITHOUT PTSD OR non-veterans)? Please describe what you have observed.

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