

Improving the Management of Severe Behavioural and Psychological Symptoms of Dementia (BPSD) in Hospitals

Experience of Hospital Staff
regarding Dementia and BPSD
in Victorian Health Services

Final Online Report

Prepared by:

National Ageing Research Institute (NARI)

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ABBREVIATIONS

ACEM	Australian College of Emergency Medicine
AIHW	Australian Institute of Health and Welfare
ANUM	Associate Nurse Unit Manager
BPSD	Behavioural and Psychological Symptoms of Dementia
CDAMS	Cognitive, Dementia, and Memory Service
CNC	Clinical Nurse Consultant
DA	Dementia Australia
DH	Department of Health
ED	Emergency Department
GEM	Geriatric Evaluation and Management
HREC	Human Research Ethics Committee
MOOC	Massive Open Online Course
NARI	National Ageing Research Institute
NUM	Nurse Unit Manager
OVA	Occupational Violence and Aggression
RACF	Residential Aged Care Facilities
SSA	Site Specific Assessment
VGTP	Victorian Geriatric Training Program

EXECUTIVE SUMMARY

Hospitals are known to be challenging places for people with dementia. Numerous physiological and psychosocial factors associated with being acutely unwell, combined with an unfamiliar and often unsuitable physical and social environment, can exacerbate symptoms of dementia. These new or changing symptoms can be difficult to manage, cause significant distress to patients, family members, staff and other patients, may result in harm to people with a dementia diagnosis or to others, and result in increased morbidity and mortality.

Behavioural and Psychological Symptoms of Dementia (BPSD), in particular, pose significant risks for individuals, the community and the healthcare system. Evidence shows they are associated with lower functional abilities and poorer prognosis, increased burden on caregivers, higher costs of care and earlier institutionalisation than those with dementia who do not demonstrate BPSD. In addition, patients with BPSD who require hospitalisation may have delayed discharge due to low availability of suitable accommodation.

This study of staff experience forms part of a larger project titled '*Improving the Management of Patients with Severe Behavioural and Psychological Symptoms of Dementia (BPSD) in Victorian Hospitals*' conducted by the National Ageing Research Institute (NARI) on behalf of the Victorian Department of Health (DH). The results from all components of the project will help to inform service delivery and the development of a best practice model of care for patients with BPSD in Victorian public hospitals.

The primary objective of this component was to explore the experience of hospital staff regarding the care of older patients with dementia and BPSD in Victorian health services. A series of semi-structured interviews were conducted to identify challenges and opportunities relating to staff education and training as well as perceptions and experiences of care provision including strategies that support good care, examples of poor care, opportunities to improve care, needs of vulnerable patient populations and the impact of the environment.

Ethical approval for this study was obtained from Austin Health Human Research Ethics Committee (HREC) on July 6th, 2021 (HREC/75588/Austin-2021).

Key Findings

A total of 15 interviews were conducted in May and June 2023, with one interview including two participants. The interviews were conducted with healthcare professionals from six different health services, consisting of five metropolitan services and one regional service, with the following range of roles: Medical - 7 interviews (5 Consultant Geriatricians, 1 ED Registrar); Nurse Unit Manager (NUM)/Associate Nurse Unit Manager (ANUM) - 8 interviews (6 NUM or ANUM roles, 2 from acute and 4 from sub-acute settings); Clinical Nurse Consultants (CNC) – 2 interviews (1 Behavioural Clinical Nurse and 1 Cognition Nurse Consultant); and Allied Health – 1 interview (Physiotherapist working in a sub-acute setting). Interviewees had varying levels of experience in the health sector, with a mean of 20 years (range 5 – 40 years). In specifically working with people with dementia, the mean was 15 years (range 1 – 24 years). When asked to rate their knowledge of dementia on a scale of 0 to 10, the mean rating from interviewees was 7.9 (range of responses varied from 6 to 10 out of 10).

Overall, participants emphasised that the current availability of services, both within and outside hospitals, is insufficient to meet the needs of individuals with dementia and BPSD. Disparity between existing policies that discourage pharmacological strategies in general ward environments and the practical challenges of implementing non-pharmacological alternatives effectively was also widely acknowledged. Participants highlighted the unsuitability of hospitals for managing patients with complex needs, suggesting that an ideal solution would involve providing care in a home setting – either a private residence or residential aged care.

In addition, many interviewees expressed feelings of sadness, frustration, and exhaustion, at times feeling overwhelmed due to the limitations and difficulties faced in providing appropriate care for individuals with dementia and BPSD in hospital. The safety of staff and other patients was a recurring concern. Despite this, majority of participants expressed their commitment to assisting others in finding practical solutions and addressing the needs of patients. Many indicated that they have learned to advocate and speak up on behalf of patients with BPSD, recognising the need to address the challenges they face and improve their care.

1. BACKGROUND

1.1 Dementia and Severe BPSD in Hospitals

Dementia is recognised as a significant and growing issue for health and aged care services in Australia. While dementia is not an inevitable or normal part of the ageing process, dementia was the leading cause of death of women and the second leading cause for men in 2020.¹

The term “dementia” describes a group of conditions characterised by gradual impairment of brain function, which impacts daily function. Dementia symptoms include difficulties with memory and thinking, communication and speech, and/or mobility, and changes in personality and behaviour. For people formally diagnosed with dementia, difficulties in communicating and expressing needs may manifest in many ways. The Behavioural and Psychological Symptoms of Dementia (BPSD) refer to symptoms of dementia such as mood disturbances, hyperactivity-type symptoms, psychotic symptoms, changes in appetite, hoarding, night-time behaviour disturbances and “wandering” and can affect between 60 and 90% of people with dementia to varying extents.² These symptoms often have a significant impact on people with dementia, carers and family, and have been associated with reduced functional ability, premature admission to residential care, increased hospitalisation rates, and increased stress for carers and for the person with dementia.³

The use of the term ‘BPSD’ is controversial as such symptoms may manifest because of the circumstances and situations perpetuated by other people and by external environments, and also from physical causes (such as medication side effects, undetected or untreated pain or discomfort, infections).³ However, the term is frequently used in clinical contexts and in the literature alongside other terminology such as changed behaviours, responsive behaviours, unmet needs, behaviours of concern, challenging behaviours and non-cognitive or neuropsychiatric symptoms of dementia.

Hospitals are known to be challenging places for people with dementia, particularly those presenting with BPSD. Numerous physiological and psychosocial factors associated with being acutely unwell, combined with an unfamiliar and often unsuitable physical and social environment, can exacerbate symptoms. These new or changing symptoms can be difficult to manage, cause significant distress to family members, staff and other patients, pose a significant risk of harm to patients themselves or to others, and result in increased morbidity and mortality.

1.2 ‘Improving the Management of Patients with Severe BPSD in Victorian Hospitals’ Project

A key issue identified by the Victorian Sub-acute Executive Peak Body in 2019 was whether Victorian health services have the capacity to meet the needs of a growing number, and increased severity, of people presenting and being admitted to hospitals with BPSD. A preliminary benchmarking survey of nine metropolitan and three regional health services in Victoria revealed that all health services provide care for patients with dementia and BPSD in sub-acute settings, but individual models of care (including management approaches and patient pathways relating to relevant emergency and acute care settings) varied significantly between health services.⁴ In addition, a number of challenges to achieving a responsive Geriatric Evaluation and Management (GEM) service, the most common specialist model of care used in Victoria for patients with dementia and BPSD, were identified. Challenges included workforce recruitment, retention, level of skill, and access to specialist mental health services, and issues relating to the built environment.

Since the commencement of this project in 2019 there have been a myriad of issues for hospitals relating to care of older people due to the COVID-19 pandemic. Across Australia the COVID-19 pandemic placed and continues to impact service provision in hospitals and residential aged care facilities (RACF). In Victoria, at least 191 RACF experienced at least one COVID-19 outbreak in the early months of the pandemic. Transfer to hospital was a common response for residents who tested positive for COVID-19 and required medical care. Many of those transferred from RACF to hospital had a diagnosis of dementia and the challenges in managing BPSD were exacerbated.

In conjunction with the Victorian Department of Health (DH), the National Ageing Research Institute (NARI) was commissioned to undertake a comprehensive review of the management of patients with severe BPSD in Victorian Hospitals (*Improving the Management of Patients with Severe BPSD in Victorian Hospitals* project).

This staff experience study forms part of that larger project.

1.3 Project Components

The *Improving the Management of Patients with Severe BPSD in Victorian Hospitals* project consists of multiple components. The project components include:

1. Establishment of an agreed definition of 'severe BPSD';
2. Exploration of national and international best practice principles and models of care regarding the hospital management of patients with severe BPSD through a rapid literature review;
3. Exploration of the extent and impact of severe BPSD on incidents, adverse events and outcomes in hospital settings within Victorian health services (through a population prevalence study, a point prevalence study, and a retrospective manual file audit);
4. Exploration of the local actions currently in place within Victorian health services to manage patients with severe BPSD in the hospital setting and compare these against best practice (using an online benchmarking survey); and
5. Exploration of the experience of family members* and staff relating to the current hospital management of severe BPSD within Victorian health services.

**Due to the COVID-19 pandemic, family member experience was not explored*

The results from all components of the project will help to inform service delivery and the development of a best practice model of care for patients with BPSD in Victorian public hospitals.

2. OVERVIEW

2.1 Study Aim

This current study aims to explore the opinions and experience of hospital staff regarding the care of older patients with dementia and BPSD in Victorian Health Services. This was achieved through a series of semi-structured interviews with clinicians from multidisciplinary teams working with patients who have dementia +/- BPSD in metropolitan and regional hospitals.

2.2 Study Objectives

Specific areas of interest that were to be examined during the interviews included:

1. Knowledge and confidence of staff in managing dementia and BPSD
2. Perceptions and experience of staff regarding care provision for patients with dementia and BPSD (including examples of good and poor care)
3. Staff education and training regarding dementia and BPSD
4. Care for patients with dementia and BPSD from minority groups, including those from diverse and disadvantaged backgrounds
5. Impact of the environment on patients with dementia and BPSD and the ability of hospital staff to provide quality care for this population

3. PROJECT DESIGN

3.1 Procedure

De-identified participant data was obtained during semi-structured interviews with staff from Victorian health services. Ethical approval for this study was obtained from Austin Health Human Research Ethics Committee (HREC) on July 6th, 2021 (HREC/75588/Austin-2021).

3.2 Recruitment and Consent

Site specific assessment (SSA) was obtained for the nine health services participating in the overall project over a period of eight months, with delays largely impacted by the COVID-19 pandemic. SSA approval was achieved for all health services by 23rd March 2022.

As part of the overarching project's benchmarking survey component, staff were asked if they were willing to participate in one-on-one interviews regarding their personal experiences. Individual staff advised of their interest by providing their contact details within the survey responses and were then contacted via e-mail to organise a mutually appropriate interview time. Consent was obtained prior to commencing the interviews.

3.3 Participant Characteristics

Staff from six Victorian public health services participated in the interview component. Five of the participating health services were located in metropolitan Melbourne while the remaining one represented a large regional centre (Table 1).

Table 1. Participating Health Services: Staff Experience Interviews

	Metropolitan	Regional
Participating Health Services	• Austin Health • Monash Health • Peninsula Health • St Vincent's Hospital Melbourne • Western Health	• Bendigo Health

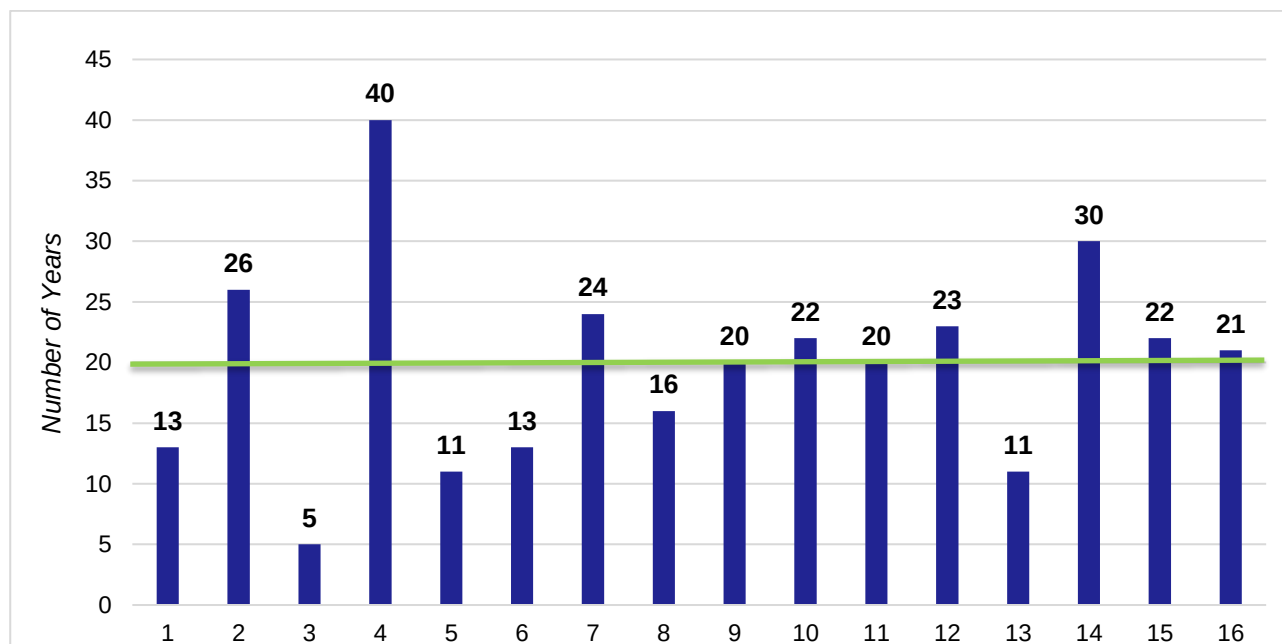
There were a range of health professions reported across the six sites including:

- NUM (Acute Ward) – 2
- NUM (Sub-acute Ward) – 2
- NUM (Unspecified) – 1
- ANUM (Sub-acute Ward) – 1
- Specialist Behavioural CNC/Cognition Nurse Consultant – 2
- Medical (Consultant Geriatrician) – 6
- Medical (Emergency Department Registrar) – 1
- Allied Health (Senior Sub-acute Physiotherapist) – 1

3.3.1. Experience Working in the Health Sector

The interviewees reported having varying levels of experience in the health service sector, ranging from 5 to 40 years, with an average of almost 20 years (19.8 years) (Figure 1).

Figure 1: Experience Working in the Health Sector (in years)



3.3.2. Experience Working with People with Dementia +/- BPSD

In terms of experience specifically working with people with dementia in hospitals, the average was just over 15 years (15.2 years), ranging from 1.5 to 30 years (Figure 2). Furthermore, the interviewees had an average of almost 12 years (11.6 years) of experience working with people with dementia who have severe BPSD, with a range of 1.5 to 22 years (Figure 3).

Figure 2: Experience Working with People with Dementia (in years)

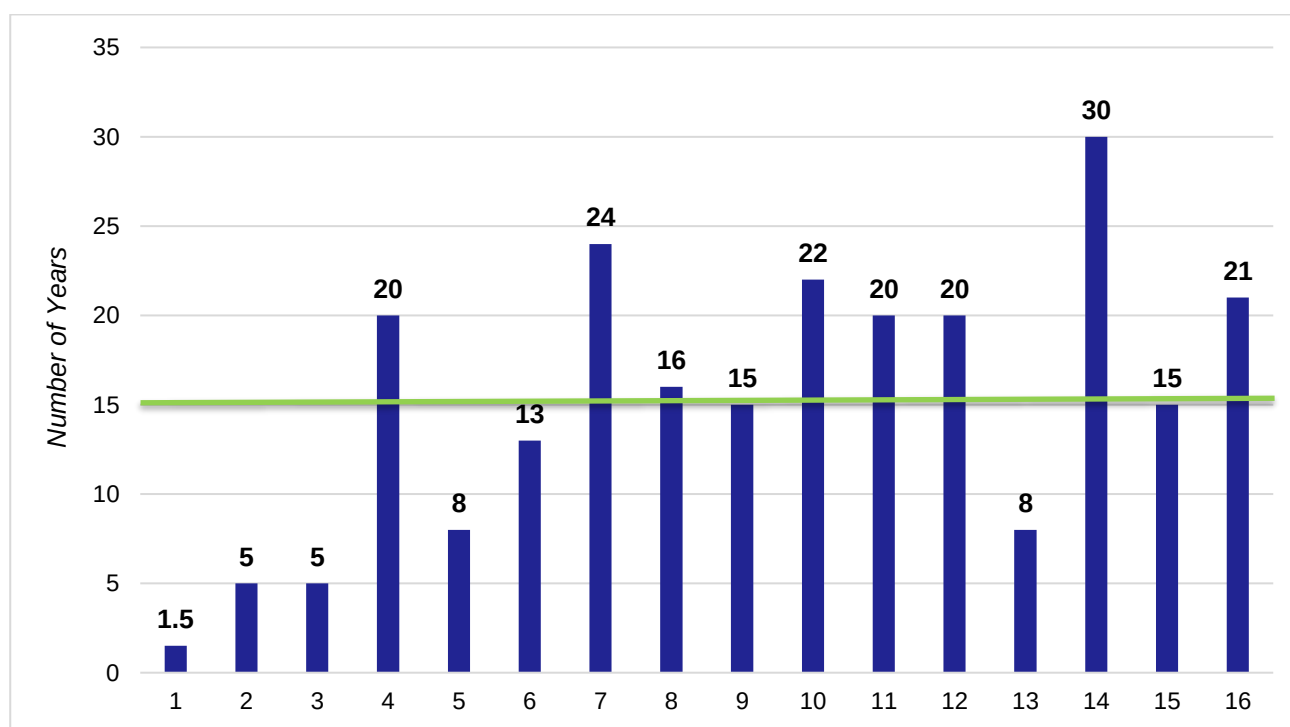
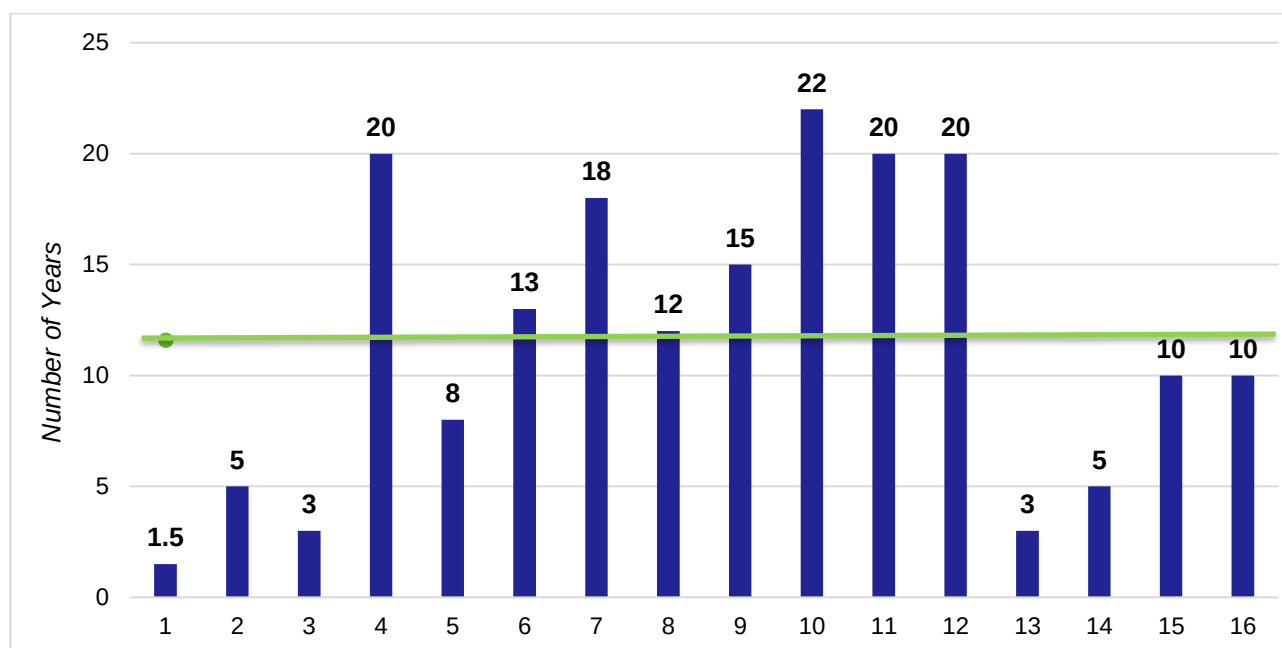


Figure 3: Experience Working with People with Dementia and Severe BPSD (in years)



3.4 Data Collection and Analysis

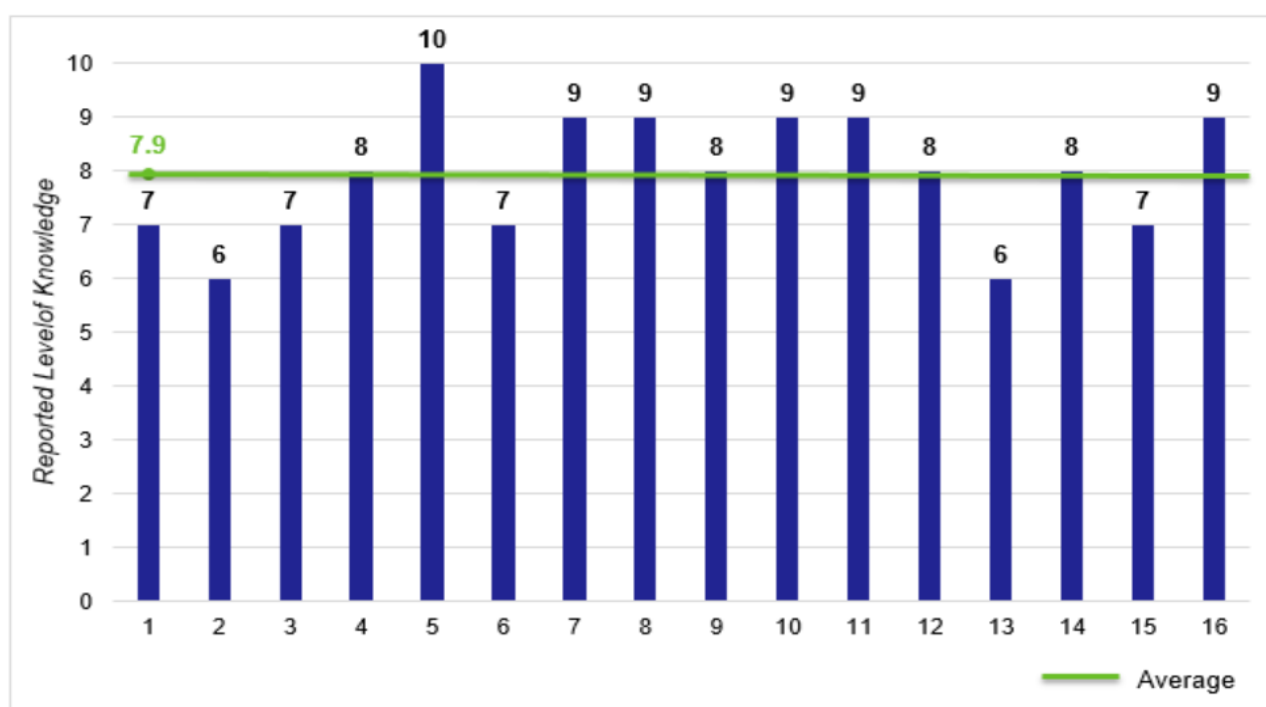
Interviews were semi-structured. Questions and prompts were developed by the NARI project team, and were informed by the previous components of the overall project. Interviews were conducted by one NARI researcher via Microsoft Teams online platform. With the consent of all participants, interviews were audio-recorded and transcribed. To ensure the confidentiality of participants, overtly identifying information (such as personal names, health service names and geographical locations) were removed and participants were not identified in the transcriptions. Two NARI researchers, who were members of the overall project team, independently used a semi-inductive thematic analysis approach to develop a coding framework, which was then further developed collaboratively. The coding framework was independently applied by these researchers to the anonymized data.

4. KEY FINDINGS

4.1 Self-reported Knowledge of Dementia and BPSD

The interviewees were asked to rate their knowledge of dementia on a scale of 0 to 10. The mean rating was 7.9, indicating a relatively high level of knowledge among the participants. The range of knowledge ratings varied from 6 to 10, showcasing a diversity in expertise and understanding of dementia and its associated challenges, including BPSD.

Figure 4: Self-reported Level of Knowledge Regarding Dementia and BPSD



The interviews revealed various initiatives and strategies undertaken by individuals, as well as suggestions for improving knowledge about dementia and BPSD.

4.1.1. Self-Initiated Education

Some of the actions that were reported to be taken by healthcare professionals to enhance their understanding of dementia and BPSD include:

- 1. University of Tasmania Dementia Massive Open Online Course (MOOC):** Several individuals have engaged in the Dementia MOOC offered by the University of Tasmania.
- 2. Undergraduate and Postgraduate University Modules:** Some interviewees mentioned completing small modules on dementia as part of their undergraduate nursing education, while others pursued postgraduate qualifications in gerontology or dementia care.
- 3. Learning through experience:** Many interviewees highlighted the value of learning on the job, accumulating knowledge through hands-on experience in caring for individuals with dementia and BPSD. Despite this, it was acknowledged that this still needs to be supplemented with formal education opportunities.

“Can’t be just on the job training – need to include classroom work e.g. role playing activities.”

- 4. Peer-Reviewed Literature:** A number of health professionals acknowledged the importance of staying updated with the latest research and evidence-based practices by reading peer-reviewed literature on dementia and BPSD.

5. **Online Resources:** Interviewees mentioned utilizing online resources from universities, often accessed through newsletters such as the one from the Australian College of Emergency Medicine (ACEM), to expand their knowledge.
6. **Dementia Support Australia:** This resource was mentioned as a means of obtaining support and guidance in managing dementia and BPSD.
7. **Clinical Practice Guidelines:** Professionals referred to clinical practice guidelines that outline stepwise management approaches, including non-pharmacological strategies, for addressing BPSD.
8. **Victorian Geriatric Training Program (VGTP) Modules:** The VGMP is an initiative of the Australian and New Zealand Society for Geriatric Medicine (Victorian Division), with funding from the Victorian Department of Health. These foundational level educational modules cover a range of issues relating to health and medical care of older people, including dementia, and are aimed at health care professionals and students.
9. **Workshops and Training Sessions:** Attending workshops and training sessions focused on dementia care and management was reported as a valuable method for enhancing knowledge.
10. **Case Studies and Sharing Ideas:** Some individuals mentioned using each patient's case as a learning opportunity and engaging in regular discussions and idea sharing with colleagues.

4.1.2. Health Service-initiated Education

While the initiatives mentioned above highlight individual efforts to improve knowledge, there were also observations regarding what health services are currently providing for their clinical staff to enhance understanding of dementia and BPSD. These include:

1. **Encouragement of Online Courses:** One health service encourages all staff members to complete the University of Tasmania Dementia MOOC, while another promotes the University of Tasmania diploma program to its staff. Some internal online modules regarding behaviour management are available however these are generally not considered mandatory.
2. **Behavioural Clinical Nurse Liaison:** One interviewee reported their health service has a Behavioural Clinical Nurse Liaison who provides education on dementia and BPSD directly to the ward staff.
3. **Formal Guidelines:** Several interviewees mentioned the availability of guidelines, including stepwise management strategies,
4. **In-services and Education Sessions:** Some health services organise regular in-services and education sessions for staff members on dementia, delirium, and changed behaviours.
5. **Delirium Focus:** Some health services incorporate dementia education into delirium education modules, but there is a need for dedicated training on dementia care.
6. **Grand Rounds, Journal Club, Morbidity and Mortality Meetings:** Ad hoc education regarding dementia and BPSD, generally led by geriatricians, is included in grand rounds, journal clubs and morbidity and mortality meetings.
7. **Collaboration with External Dementia Consultation Services:** Health services collaborate with external dementia consultation services and behavioural nurse consultants to provide practical advice and education to staff members when working with specific patients.
8. **Local Clinical Leads:** One interviewee reported their health service has a cognition local clinical lead on each unit, providing education and study days to improve staff training.

“It would be good professionally to have a network of cognition leads/specialists.”

4.1.3. Challenges to Improving Staff Knowledge

Despite the education opportunities outlined above, some interviewees mentioned that there are no formal education opportunities specifically dedicated to the pathophysiology of dementia and BPSD, or training regarding non-pharmacological management strategies.

Furthermore, in organisations where policies and guidelines were available to improve knowledge and support clinical practice, these were often considered by staff to be inconsistent and/or unhelpful.

“Policies say ‘non-pharmacological methods first’ but there is no education on what these should be so education about implementing the policy.”

Overall, interviewees agreed that more formal, multi-disciplinary education on dementia care for nurses, junior doctors and allied health was required. Suggestions included a dementia-specific online learning module for all staff to complete and models of care that incorporate an organisation-wide dementia CNC supported by dementia care champions on every ward (including the emergency department). Additionally, the need for better undergraduate training to support graduates was highlighted.

“Universities need to ensure graduates in all disciplines have these skills – now there are so many more cases in hospitals – its harmful to “release” graduates into these settings without training – harm to patients as new grads can be condescending, misunderstanding.”

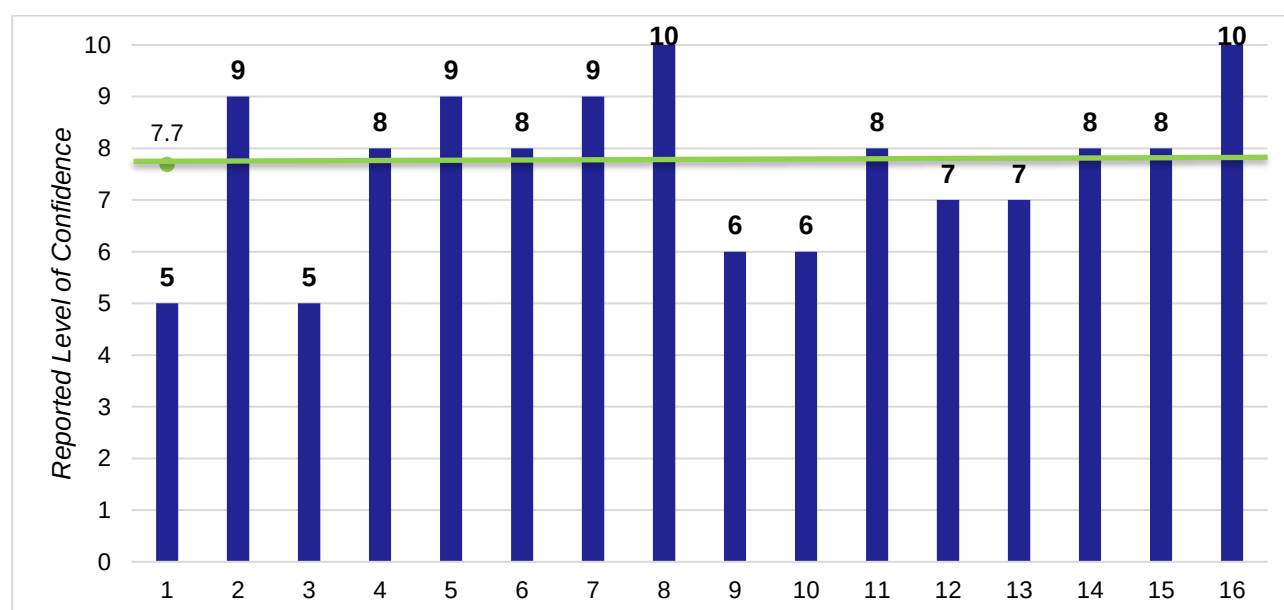
Targeted education for the range of clinical and non-clinical staff who interact with patients with dementia and BPSD in hospitals was also considered critical to improving care provision, proactively managing BPSD, reducing incidents/adverse events and improving both care experience and health outcomes.

The Specials need to have education and skills, otherwise they are just sitters – this feeds into the problem as people are feeling like they are being “baby sat.”

4.2 Self-reported Confidence in Managing Patients with Dementia and BPSD

The interviews revealed varying levels of confidence among healthcare professionals in their ability to effectively manage patients with dementia and BPSD. The participants were asked to rate their confidence on a scale of 0 to 10, with a mean score of 7.7 and a range of 5 to 10.

Figure 5: Self-reported Level of Confidence in Managing Patients with Dementia and BPSD



Responses regarding self-reported confidence in managing patients with dementia and BPSD included:

1. **De-escalation and Making Changes:** Some participants reported feeling they have the knowledge and skills to de-escalate behaviours and make appropriate changes in management strategies.

“I have situational awareness, make sure they is always two exits, use security as needed.”

2. **Access to Resources and Support:** A number of participants acknowledged that being part of a larger service with access to resources such as code grey (emergency response system), highly skilled nurses, and adequate staffing ratios increased their confidence, as they have support available when needed.
3. **Variations in Confidence:** Confidence levels varied among participants working on different units within the healthcare setting. Units such as the emergency department, high acuity units, and surgical units were identified as struggling with the care of patients with dementia and severe BPSD.

“I have some tricks up my sleeve but I am not fully confident due to experiencing verbal and physical incidents – I have some doubt.”

4. **Perceptions and Experiences of Care Provision:** While some participant perceived that care is provided to a reasonable level, others expressed that care is not done well or it is managed poorly.
5. **Collaboration between Medical and Nursing Staff:** The interviews highlighted the importance of collaboration between clinicians in managing patients with dementia and BPSD. Medical staff adjust medications to address behavioural symptoms however the nursing staff, who are present 24/7, bear the responsibility of managing these symptoms on an ongoing basis.

4.3 Experience of Clinical Care Provision

4.3.1. High-Quality Dementia Care

Table 2 outlines examples of good clinical practice identified by interviewees for people with dementia +/- BPSD in hospital. These strategies include environmental modifications, enhanced multidisciplinary collaboration and training, aim to support comprehensive care provision, patient well-being and quality of life.

Table 2: Examples of High-Quality Dementia Care Identified by Interviewees

Clinical Care Provision	
Cognitive Impairment Identifier	Implementation of a cognitive impairment identifier to assist in recognizing and addressing the specific needs of patients with dementia.
Sunflower Tool	Introduction of the Sunflower Tool, which is used by staff to enhance care provision for patients with dementia and BPSD.
Behavioural Support Plan	Implementation of a behavioural support plan that includes identifying triggers and finding ways to support patients and their families.
Non-Pharmacological Strategies	Greater recognition and utilisation of non-pharmacological strategies e.g. non-stimulating environments; allowing sufficient time for patient needs.
Individualized Activities	Introduction of dementia-specific activities such as newspapers, TV, and repurposing the cooking area to meet patient interests and needs.
Delirium Management	Improved identification and management of delirium, which is reported to positively impact the confidence of general medicine registrars in differentiating and, subsequently managing, BPSD.
Multidisciplinary Approaches	Behaviour huddles involving multidisciplinary teams, including psychiatrists, neuropsychologists, local nurses, and medical registrars, to address complex cases and improve care coordination.

Collaboration with Families	Involvement of family members in the care planning and provision, including bringing personal items like blankets and music for the patients.
Intensive Observation Room (IOR)	"Cohorting of patients" via an Intensive Observation Room – a 4-bed room usually consisting of patients from general medicine. Assigned consultant is either a general physician or a geriatrician, with a cohort of nurses having been specifically trained in the care of patients with dementia.
Resources	
Dementia Management Unit	The establishment of a specialized unit with experienced geriatricians, diversional therapists, and good nursing care for patients with dementia.
Patient Engagement	Utilisation of iPads on wheels to provide entertainment, such as listening to sports events, and culturally appropriate music.
Toolbox of Small Activities	Implementation of a toolbox of small activities on the ward to engage and stimulate patients with dementia
Workforce	
Access to Specials	Provision of access to patient specials, including student nurses who receive additional training in dementia care.
Dedicated Staff and Teamwork	Recognition of the dedication and teamwork of staff in providing quality care for patients with dementia.
Consultation and Support Services	Availability of support and consultation services – consultant liaison, delirium CNC, behavioural/psychiatric CNC, and dementia nurse practitioners.
Transitional Support	Aged Care Liaison Service/consultation services to assist with transitions.
Education and Training	
Mentoring and Training	Mentoring of staff in non-pharmacological strategies and continuous training to improve their skills in managing dementia and BPSD.
Training and Awareness	Staff training and expectation that all staff members read the "About Me" form for each patient to understand their individual needs.
Physical Environment	
Sub-acute Environments	Acute ward staff perceive sub-acute environments as better suited for patients with dementia and BPSD.
Environmental Upgrades	Changes to ward environments based on Dementia Australia (DA) principles and guidelines to create a more homely and/or dementia-friendly atmosphere.
Organisational Culture	
Harm Minimisation Approach	Adoption of a harm minimisation approach with a focus on cognition, falls prevention, and overall patient well-being.
Documentation and Handovers	Better documentation and handover practices, including flagging BPSD, recording top care tips, and utilizing risk screening tools.
Terminology Improvement	Increasing recognition and use of appropriate terminology when discussing and managing dementia and BPSD.

Multiple interviewees provided details regarding “behaviour huddles”, which may involve cognition CNCs, occupational violence and aggression (OVA) prevention teams, mental health representatives from psychiatry/neuropsychology, local nurses and medical registrars. These reportedly occur at regular, allocated times or ad hoc as needed.

“Behaviour Huddles incorporating a multidisciplinary team which includes psych, risk team and allied health are helpful – it changes the care.”

Non-clinical staff were also identified as supporting the provision of “good care” for patients with dementia and BPSD in hospitals. These included ward clerks and security guards who were reported to commonly identify and/or de-escalate challenging behaviors and provide meaningful engagement.

“One of our security guards is very helpful, stays with patients, has a morning cup of tea with them and engages them.”

4.3.2. Low-Quality Dementia Care

Contributing factors to low-quality care and clinical practice for individuals with dementia and BPSD expressed by interviewees are outlined in Table 3.

Table 3: Examples of Low-Quality Dementia Care Identified by Interviewees

Clinical Care Provision	
Poor Identification of Patients with Dementia	- It's difficult to identify patients with dementia in hospital – if not able to identify, staff do not know how to manage. - Many screening tools are used but these often have no meaning or associated action plan. Poor compliance with 4AT completion (assessment for delirium detection).
Medication-Focused Approach	- While medical staff may adjust medications to address behavioural symptoms, nursing staff (who are present round the clock) have the primary responsibility of managing these behaviours. - There is often a heavy reliance on medication adjustments without comprehensive non-pharmacological strategies.
Use of Restrictive Practices	At times, restrictive practices are used – these occur because there are not enough resources for less harmful non-pharmacological strategies.
Inconsistent Care Provision	- Mixed perception of the quality of care provided to patients with BPSD. - While some units offer care to a reasonable level, there are instances where care is managed poorly, leading to substandard outcomes for patients.
Lack of Meaningful Stimulation	On many wards, particularly general medical wards, there is a lack of structure to the day for patients. Patients are often restricted to their rooms with nothing to do – no activities or other people to engage with.
Inappropriate Care Settings	- There is no pathway for direct access into sub-acute GEM or dementia-specific GEM for those patients who may not need an acute ward. - Often specialised dementia management units are not able to look after as many patients as need this service so they end up on general wards – hard to provide the type/amount of care required, less space, more noise. This also means that patients without cognitive impairment are in wards with patients with cognitive impairment. - The emergency department, medical and specialist units were also identified as not having holistic approaches to the care of these patients.
No Access to Shared-Care	Patients with BPSD are often either under a Geriatrician or an Old Age Psychiatrist – there is no shared care model.

Barriers to Discharge	• RACF often refuse to take patients, especially those with severe BPSD. • Significant numbers of patients are on the ward for an extended time (including those awaiting Victorian Civil and Administrative Tribunal for decision on Guardianship).
Resources	
Limited Resources	• Some units lack necessary resources/support to manage patients with dementia and BPSD effectively. This includes a shortage of highly skilled nurses (e.g. cognition CNC), inadequate staff ratios, and limited access to specialised services e.g. planned Code Grey staff to provide backup. • Physical resources to support diversional therapy often not available.
Workforce	
Negative Attitudes	• Sometimes staff attitudes towards these patients can negatively impact care.
Variation in Confidence Levels	• Confidence in effectively managing patients with severe BPSD varies among different units. The emergency department, high acuity and surgical units often struggle providing appropriate care for people with dementia +/- BPSD.
Limited Access to Specialised Staff	• The availability and accessibility of diversional therapists, dementia nurses, and other specialised personnel may be limited, resulting in a lack of tailored activities and support for patients with dementia and BPSD.
Education and Training	
Insufficient Training and Knowledge	• Staff members, particularly in medical and surgical units, may lack sufficient training and knowledge in managing the complex needs of patients with dementia and BPSD. This can lead to suboptimal care provision and difficulties in de-escalating challenging behaviours.
Lack of Understanding and Implementation	• Education of medical staff not appropriate - new registrars need to be educated on appropriate interventions. • Some staff struggle with understanding and implementing non-pharmacological strategies, such as creating non-stimulating environments and allowing adequate time for patients' needs.
Physical Environment	
Environmental Factors	• Inadequate physical environments that do not align with dementia-friendly principles and guidelines can contribute to low-quality care. • Insufficient upgrades and modifications may result in a less homely and supportive atmosphere for patients with dementia.
Organisational Culture	
Communication and Collaboration Challenges	• Ineffective communication and collaboration between different teams and stakeholders can hinder provision of high-quality care. This includes limited coordination between medical, nursing, and allied health staff, as well as inadequate involvement of family in care planning and decision-making.
Ineffective Policies, Procedures and Guidelines	• Cultural and structural protocols allow for antipsychotic medication prescription and restrictive practices. • Clinical practice guidelines do not seem to explain how pharmacological strategies and non-pharmacological strategies should relate.
Lack of Continuous Improvement	• In some cases, there is a lack of systematic documentation and evaluation of care strategies, including both successful and unsuccessful approaches. This hinders the ability to learn from past experiences and make necessary improvements in care provision.

There was overwhelming feedback from interviewees regarding a lack of staff awareness regarding how to manage patients with BPSD including an understanding of why signs and symptoms occur. This was reported to include nurses and medical staff who are not Geriatricians.

“There have been occasions when staff “argue” with person with dementia – they are not aware why this is inappropriate.”

While a lack of ‘specials’ was identified as an issue, concerns were also raised about the ability of these staff members in being able to appropriately support the care of patients with dementia and BPSD.

“Specials are not often trained – they can make the situation worse by staring and watching. They need to be trained to engage with and interact with the patient; it’s better if it is a friend or carer, not a security or ‘body guard.’”

4.4 Patients from Diverse and Disadvantaged Backgrounds

During the interviews, it was identified that patients with dementia +/- BPSD from different ethnic, cultural, socioeconomic and marginalised groups had distinct needs and faced additional barriers to care in hospitals.

4.4.1. Role of Family Members

Participants reported that family members play a variety of important roles in supporting the management of patients with dementia and BPSD from diverse backgrounds, including cultural and linguistic diversity (CALD), who are in hospital. These include being present on the ward to provide familiar interactions with the patient as well as assisting staff in providing information about background stories and routines. Community leaders are also often engaged to support patients and family members. Despite this, some interviewees suggested that family members were often unable to come into the hospital due to other caring responsibilities.

“Coming into hospital can be difficult for families – there can be guilt and shame for the way their relative is behaving.”

4.4.2. Managing Communication Barriers in those from non-English speaking backgrounds

A number of participants reported that patients with dementia from non-English speaking backgrounds experienced huge and disproportionate challenges within the hospital environment. While assistive translation technology (e.g. google translate), formal interpreting services (face-to-face mode generally preferred over phone and face-time however not always available) and bi-lingual staff members were regularly used to assist in facilitating communication with these patients, some interviewees reported that often there is no way of facilitating communicating. Another participant highlighted that, as the disease progresses, many patients from non-English speaking backgrounds not only lose any ability they had to speak English but also lose their native language to a degree that it is not understandable to an interpreter as well.

“Often there is no way of communicating. People tend to raise their voices which can be frightening and trigger BPSD symptoms.”

4.4.3. Supporting Those who are Socially Isolated

Interviewees acknowledged that social isolation poses additional challenges for the care of patients with dementia and BPSD, with staff often needing to advocate for them on their behalf. There was a feeling that isolation both during and following the COVID pandemic has increased the burden of dementia and BPSD.

“A group of vulnerable patients prompted a change in staff to try new initiatives – these were a cohort of socially isolated people living with dementia who had no family, no money, no clothes. So often these people are ‘voiceless’ – there needs to be dementia care specific for them.”

One participant also raised concerns regarding the management of neurodiverse people with dementia, highlighting the potential impact on behaviours when they move into the shared space of hospital and asking – how can their “routines” from home be replicated?

4.5 Environmental Factors Impacting Care

4.5.1. Physical Environment

Specific issues raised by participants relating to the physical environment, and its influence on the health and well-being of individuals with dementia, included:

1. **Room Allocation:** It was felt that there is a need for more single rooms to accommodate the specific needs of patients with dementia, including privacy and reduced sensory stimulation. Placing patients closer to the nurse's station for high visibility often occurs to provide better supervision and reduce potential risks.
2. **Room Set-up:** Ward rooms are often small and not designed as single rooms, which hinders privacy and individualized care. Suggestions from participants included minimizing furniture and providing low/low beds to enhance safety for patients. Tight spaces and shared rooms create an environment that restricts movement and personal space for patients with dementia.
3. **Common Ward Areas:** Many interviewees reported that their hospital environments lack essential functional amenities in general areas (such as sofas, TVs), with one reporting that patients are often found sitting in front of linen cupboards due to a lack of suitable seating options. Furthermore, signage on many wards is not good – in particular, the colours used are not suitable for patients with dementia.
4. **Access to Outdoors:** Interviewees reported that many patients express a desire to go outdoors to wander and feel a sense of freedom, emphasizing the importance of access to nature in reducing agitation. However there is a reported lack of outdoor areas/access, which prevents patients from enjoying natural light and fresh air. In hospitals where outdoor areas are available, staff members often lack confidence in taking patients off the ward to access them, limiting patients' opportunities to benefit from the environment.

“There is no outside space – many patients like to wander around and need somewhere to wander to. They need to feel “free”!”

5. **Windows:** Windows are often kept closed, blocking natural light and preventing patients from experiencing the benefits of sunlight and fresh air.
6. **Flooring:** Speckled floors are commonly found in some care environments, however these can be visually distorting and potentially disorienting for individuals with dementia.
7. **Noise and Lighting:** Hospitals are generally noisy environments, which can increase agitation among dementia patients. Inadequate lighting affects visibility and can contribute to a depressing atmosphere.
8. **Resources and Activities:** Multiple participants reported there is also limited access to resources, such as books and magazines, which hampers patients' engagement and diversion. The absence of purposeful recreational activities and spaces for leisure and social engagement further affects the well-being of individuals with dementia. This is exacerbated by a lack of dedicated diversional therapists.
9. **Stimulation Levels:** Insufficient variety of specific areas with different levels of stimulation (both high and low, as required) limit the adaptability of the environment to meet the changing needs of patients with dementia. Medical wards, in particular, were highlighted as being too busy and overstimulating for patients with dementia and BPSD.
10. **Emergency Department Environments:** The chaotic emergency department environment was raised by many interviewees as a challenge for patients with dementia and BPSD.

“The ED environment is fraught – high acuity, high traffic, no windows (which is disorienting), the locks are invariably not working, absence of gentle sensory stimulation without buzzes and beeping, the cubicles are set up with sheer curtains rather than as rooms so there is ‘sensory contamination’ which increases agitation.”

Despite this, there were a number of examples provided by interviewees of environmental features that support the management of patients with dementia and BPSD in hospital. These included:

- **Dementia Management Unit**
 - Large outdoors area
 - Lounge with TV
 - Common areas
- **Aged Psychiatric Unit**
 - Communal dining area
 - Broken into areas of 10
 - Some areas are “homely”
- **Specifically built ‘dementia-friendly’ Unit**
 - Internal courtyard
 - Includes seven double rooms
 - All beds set to a low height (low-low beds)
 - Alarms are connected to phones to minimize loud noises, except for chair alarms

Participants recommended that hospitals should adhere to DA guidelines to improve the suitability of ward environments in caring for patients with dementia and BPSD.

4.5.2. Organisational Environment

The workplace environment and culture of the organisation was also highlighted as critical in impacting the care of patients with dementia in hospital.

“Big difference in 2 wards in our hospital – the cultures are different and this seems to impact on the care. One has a reporting culture with good leader who encourages staff to speak up about OVA, the team is more cohesive, has high levels of communication, shares resources and has huddles. The other ward has chaotic energy and is more fractured.”

Participants suggested that organisational attitudes, both internal and external, towards the management of patients with dementia and BPSD had significant influence on care provision. It was reported that some patients with extreme BPSD are “stopped at the doors” of hospitals and, subsequently, not able to access acute care. In these cases, it was suggested that these patients need to have direct link to a Geriatrician or Psychiatrist-led services.

“Ambulance and ED are not transporting and admitting patients with severe or extreme BPSD – there is no appropriate place for these patients. Also aged psychiatry are pushing back seeing them.”

Furthermore, there was also a perceived reluctance of RACF to manage patients with challenging behaviours, with many reported to refuse to accept those who are considered ready for discharge from hospital. This is compounded by the high demand for private residential care, meaning that facilities are not needing to take patients with more complex care requirements.

RACF are reluctant to take these patients back due to the change in behaviours. Facilities are saying “too hard to manage.”

Despite this, it was felt that RACF seem to be able to manage the care of patients with dementia and BPSD better – perhaps due to more realistic expectations, and greater acceptance, of challenging behaviours. It was also reported that residential care outreach services, which allow follow up at the facility by Geriatrician or Geriatrician Registrar following discharge, enable the transition to be as smooth as possible and provide good support for RACF staff.

4.5.3. Workforce Environment

Attitudes and expectations of hospital staff, both frontline and management, were also identified as another key factor in the care provided for patients with dementia and BPSD.

Some staff are reluctant to call for help – there is a culture of “I’ll be right” – we need to educate staff to think that these are complex behaviours and that seeking help is not failure.”

There was an overwhelming feeling that frontline staff were dedicated, worked well as a team, adopted a person-centered approach and were good at recognizing signs of escalation. However concerns were also raised that some staff do not have the knowledge, skills, and confidence to effectively manage patients with dementia and BPSD, and are not provided with adequate education/training from their respective organisations.

Positive influences on the workforce reported by interviewees included:

- Managers who feel responsible for other staff help educate them as much as possible
- Mentoring of staff in non-pharmacological strategies has been occurring
- Deliberate rostering of multi-cultural nursing staff to support communication
- Set expectation of the need to read the “About Me” form for each patient
- Advent of electronic medical record which allows emergency department registrars and other staff to follow patient journeys through a file review to reflect on practice and help with care
- Monthly education regarding dementia, delirium and changed behaviours available for all staff
- Safer staff legislation which provides extra nursing staff for night shift has just come in

4.5.4. Impact of COVID

A number of participants mentioned specific examples of the impact that the COVID-19 pandemic has had on the presentation and management of patients with dementia and BPSD in hospital.

“COVID has been a big change. Before, there were activities – during COVID, none. Now we have to start to engage more – more visitors, buying some colouring books, textas, and newspapers delivered which can be read by patients with their morning cup of tea – to match home routines and see more engagement.”

In particular, it was identified that the social isolation experienced both during and following the pandemic has increased the burden of dementia and BPSD, and results in more challenging behaviours that are increasingly difficult to manage. This has, in turn, meant that more patients with dementia and BPSD are presenting to hospital and being spread across wards/units which are not necessarily set-up to manage the care of these patients.

“Since COVID patients have been becoming more severe – in secure GEM, have extreme signs and symptoms so on GEM the case mix is more of those presenting with mild BPSD – staff (ward staff and Drs) have got better at managing mild BPSD. However the really severe BPSD are difficult to manage, this has not improved. They are staying for long periods. Strategies are not making a difference.”

Concerningly, there was a feeling of sadness, guilt and helplessness from interviewees regarding the current, and future, management of patients with dementia and BPSD in hospital. Staff were reported to be “weary” and concerned about the ongoing safety of other patients and fellow co-workers.

“I worry that without attention this will become a bigger problem and the care of people with BPSD will get worse – there will be an intergenerational effect also.”

5. LIMITATIONS

There are some limitations associated with the survey methodology that may potentially impact the accuracy and interpretation of the information obtained:

1. **Self-reporting Bias:** The findings presented in this report were obtained via self-report. This type of methodology introduces a number of biases which may affect the accuracy of the data, including social desirability bias where the interviewees provide certain responses in order to make a good impression rather than reporting accurate information.
2. **Self-selection Bias:** Participants in the interviews were obtained through voluntarily self-nomination. It is therefore possible that these clinicians represent a biased group of hospital staff with a particular interest in the management of patients with dementia and BPSD. Different findings may have been obtained by a random sample of staff representing a variety of wards and professions.
3. **Question Bias:** Despite careful and considered interview design, some questions and prompts may have unintentionally been leading, ambiguous and/or open to (mis)interpretation by interviewees. This was minimised by a semi-structured interview approach with ample opportunities for participants to ask for clarification and expand on their responses.

6. CONCLUSION

Dementia is recognised as a significant and growing health and aged care issue in Australia. BPSD, in particular, is challenging for individuals, the community and the healthcare system. It is associated with lower functional abilities and poorer prognosis, an increased burden on caregivers, higher costs of care and earlier institutionalisation than those with dementia who do not demonstrate BPSD. In addition, patients with BPSD who require hospitalisation may have delayed discharge from hospital because of the lack of availability of suitable accommodation.

Exploring staff opinions and experience of care provides critical insights and guidance on how to improve service provision and overall hospital performance. Findings from the interviews conducted in this study provide additional understandings, insights and reflections regarding the current management of patients with diagnosed, suspected or probable dementia and BPSD in various inpatient settings from the perspective of the multi-disciplinary team.

Overall, clinicians emphasised that the current availability of services, both within and outside hospitals, is insufficient to meet the needs of individuals with dementia and BPSD. There was consensus regarding the necessity of a geriatric-specific emergency department that admits patients to dementia-friendly wards in a timely manner, emphasising the importance of specialised care pathways and models for patients with dementia and BPSD. Disparity between existing policies that discourage pharmacological strategies in general ward environments and the practical challenges of implementing non-pharmacological alternatives effectively was also widely acknowledged. Participants highlighted the unsuitability of hospitals for managing patients with complex needs, suggesting that an ideal solution would involve providing care in a home setting.

The demanding nature of providing care for individuals with BPSD was also reflected in participants' remarks, with many feeling overwhelmed, distressed and helpless in constantly dealing with urgent issues. Feelings of guilt were expressed by many staff who felt unable to offer the highest level of care due to the identified existing limitations and constraints. Participants indicated that they have learned to advocate and speak up on behalf of patients with BPSD, recognising the need to address the challenges they face and improve their care. Despite this, concerns were raised about the potential worsening of care for people with dementia and BPSD if adequate organisational attention is not given to the existing challenges.

Addressing these issues is crucial to enhancing the quality of care for individuals with dementia and BPSD. Designing dementia-friendly wards, establishing appropriate patient pathways, promoting staff engagement, involving families/carers in care, improving interdisciplinary collaboration, prioritising non-pharmacological management strategies and enhancing community-based services are fundamental. However this should be underpinned by the implementation of comprehensive education and training programs, adequate resource allocation (material and workforce) and strong clinical governance in order to achieve better outcomes for patients, their families/carers and staff. The importance of integrating patient stories and experiences into care provision and quality improvement to ensure the best possible outcomes for patients with dementia and BPSD was also identified. While participants acknowledged the limitations of their roles in completely resolving the challenges associated with dementia and BPSD care, they expressed their commitment to assisting in finding practical solutions and addressing the needs of patients.

This project confirms the urgent need for improved services and specialised care for individuals with dementia and BPSD in Victorian hospitals. The concerns expressed by participants underscores the importance of addressing these issues in a timely and sustainable manner to ensure better outcomes for patients and their families and carers, and alleviate the challenges faced by healthcare professionals providing care for this vulnerable population.

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