



Experiences of Older Adults with Dementia and Behavioural and Psychological Symptoms of Dementia (BPSD):

Understanding Healthcare Access in Residential Settings

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About HCCA

The **Health Care Consumers' Association** (HCCA) is a health promotion agency and the peak consumer advocacy organisation in the Canberra region. HCCA provides a voice for consumers on local health issues and provides opportunities for health care consumers to participate in all levels of health service planning, policy development and decision making.

HCCA involves consumers through:

- consumer representation and consumer and community consultations;
- training in health rights and navigating the health system;
- community forums and information sessions about health services; and
- research into consumer experience of human services.

HCCA is committed to **consumer-centred care** as a foundation principle in all its work and to promoting consumer-centred care across the health system, within government and across the ACT community. Consumer-centred care meets the physical, emotional, psychological and cultural needs of consumers and is responsive to someone's unique circumstances and goals¹.

HCCA is a Health Promotion Charity registered with the Australian Charities and Not-for-Profits Commission.

This research is part of HCCA's Integrated Care Project, which was supported by the ACT Health Directorate.

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Executive Summary

Meeting the healthcare needs of people with dementia experiencing behavioural and psychological symptoms of dementia is challenging. This report explores how people with dementia living in residential aged care accessed healthcare and their experiences of care during hospital presentations and admissions. Additionally, this report investigates the experiences of family carers in supporting their family members who are living in residential aged care.

Five semi-structured interviews were conducted with family members of people with dementia living in a residential aged care, and one semi-structured interview was conducted with an older person with dementia living in a residential aged care.

The healthcare services older people in residential aged care most often accessed included GPs, geriatricians, physiotherapists and podiatrists. While these were most often provided by and accessed within the residential aged care, some participants accessed these services and other specialists not routinely provided by the home externally.

Access to healthcare for older people with dementia was most often supported by family carers. They played key roles in observing changes in health and organising medical appointments, facilitating transfer to and from appointments and managing medical handovers during transitions of care from the residential aged care and external care providers such as specialists or hospitals. Family carers acted as advocates, supporting person-centred care, reducing distress, and ensuring access to safe care.

When discussing their experiences of accessing care, participants recognised that healthcare professionals are trying to be dementia-informed when providing care. However, some family carers reported difficulties in working with health professionals when there were conflicts between the choice of the person with dementia and providing care that supports the best interests of the person with dementia and their family carers.

This project faced significant challenges in recruiting participants to share their experiences. Some of this was attributed to the scope of this project including the focus on experiences around hospital care. Additionally, potential family participants declined to participate due to feelings of overwhelm from trying to manage their caring obligations and life circumstances.

The findings demonstrate it is necessary for the health system to recognise the multiple and often complex roles played by family carers, even as and when older people with dementia move into residential aged care. This report identifies opportunities to provide supports for people with dementia and their family carers to reduce the burden of

caring responsibilities by expanding access to existing community supports such as transport services and publicly available doctors and care teams such as Rapid Access of the Deteriorating Aged at Risk (RADAR).

List of Acronyms

BPSD – Behavioural and psychological symptoms of Dementia

RAC – Residential Aged Care

RADAR - Rapid Access of the Deteriorating Aged at Risk

ACT – Australian Capital Territory

ED – Emergency department

GRACE - Geriatric Rapid Acute Care Evaluation

CALMS – Canberra After Hours Locum Medical Service

EPoA – Enduring Power of Attorney

Introduction

What are the Behavioural and Psychological Symptoms of Dementia?

Behavioural and psychological symptoms of dementia (BPSD) are also known as neuropsychiatric symptoms, that represent a range of non-cognitive symptoms and behaviours occurring in people with dementia². Despite being universally present during dementia, BPSD is not included in the defining criteria of the current classification system³.

BPSD include agitation, aberrant motor behaviour, anxiety, elation, irritability, depression, apathy, disinhibition, delusions, hallucinations, and sleep or appetite changes². It is estimated that BPSD affects up to 90% of all people with dementia over the course of their illness. BPSD is associated with high levels of distress for the person with dementia and their caregivers. It is linked with poor quality of life for the person and their caregivers, long-term hospitalisation, misuse of medication, and increased health care costs.

Studies have shown that BPSD for people with dementia are generally less-frequent and less severe for those in long-term care settings⁴. The most common BPSD that present in people with dementia are apathy, depression, irritability, agitation and anxiety, while euphoria, hallucinations and disinhibition are least common². Importantly, 50% of patients have at least four neuropsychiatric symptoms simultaneously.

Consistent with research, in Australia, the most common BPSD exhibited by people with dementia are agitation, physical aggression and verbal aggression and anxiety⁵. Of the people who completed an aged care assessment in 2020-2021, people living with dementia were significantly more likely to report experiencing behavioural and psychological symptoms like agitation, apathy, verbal aggression, wandering, resistive behaviour and risky behaviours than adults without dementia. Further, 21% of people with dementia experienced three or more BPSD regularly or all the time.

In 2019, it was estimated that over 50% of people living in residential aged care had a diagnosis of dementia⁶.

Dementia and BPSD in the ACT

In 2024, it is estimated that there are more than 6,000 people living with all forms of dementia in the ACT. This number is projected to increase to almost 12,300 by 2054, an increase of 104%⁷.

In 2021-22, there were 34 hospitalisations due to dementia per 10,000 people living in the Australian Capital Territory for adults aged 60 and over⁸.

Across Australia, for all hospitalisations that were due to dementia⁸,

- over 40% of people with dementia were released home in the community,
- 24% were discharged into another unit within the hospital,
- 14% of adults were discharged from the hospital to a RAC, where it was not their usual residence, and
- 5% were discharged to a RAC that was their usual place of residence.

Aims of the Study

The aims of this project were to:

1. Understand the health care needs of people living with dementia and experiencing BPSD who are living in RACs
2. Record the experiences of accessing health care whilst residing in RACs

A secondary aim of this project is to:

3. Identify the experiences of the families and informal carers of older adults living in RACs experiencing BPSD.

This project's focus on older adults experiencing BPSD and their families and carers aligns with the ACT Health Directorate and Canberra Health Services' commitments to improving care and services for older adults continually improving the quality of care provided in the ACT.

The results of this study provide insights into how RAC residents who are older and experiencing BPSD access health care and supports.

Historically, our understanding of dementia prevalence and its impacts in Australia has been constrained by insufficient data and limitations on the data being collected within health and aged care systems. While the introduction of clinical information systems and electronic health records in recent years has allowed the healthcare sector to begin to bridge these information gaps relating to dementia, the fragmented nature of health and aged care systems remains challenging.

The findings of this study will contribute to the evidence base of consumer experiences of accessing care for dementia and its related symptoms. The findings will inform decisions on the development of the new Older Canberrans Centre of Excellence. These (and other) ACT services for older adults are more likely to meet community needs if consumer insights are incorporated into their development.

Additionally, this approach is in line with the National Quality and Safety Health Service Standards' expectations regarding patient-centred care⁹.

Methods

This is a qualitative research project to elicit consumer (and carer) experiences and perspectives of accessing health care when living in a residential aged care (RAC) and experiencing behavioural and psychological symptoms of dementia (BPSD). This study was approved by the ACT Health Human Research Ethics Committee on 28 June 2024 (Reference Number: 2024.ETH.00080).

Participant eligibility and recruitment

To be eligible, participants had to:

- Be aged 60 years and above or 50 years and above for Aboriginal and Torres Strait Islander Peoples who:
- Identified as having a diagnosis of dementia and have experienced BPSD;

AND

- Living in a RAC in the ACT;
- Have presented to the Emergency Department or been hospitalised in the last two years;

OR

- Family or informal carers of eligible RAC residents.

As the focus of this project was on identifying how to improve the healthcare (including hospitals) and services available to older adults with dementia, we excluded:

- Residents under the age of 60, or 50 if they are Aboriginal and Torres Strait Islander Peoples
- Older adults living with dementia, who don't feel comfortable talking about their diagnosis or their care related to dementia
- Residents unable to provide consent themselves, or for whom consent cannot be obtained from legal guardians

An invitation to join in the study was widely disseminated through HCCA networks, newsletters and bulletins issued by community organisations that focus on providing supports for older people, carers and dementia specific services and supports. These included Carers ACT, Council of the Ageing ACT, Dementia Australia, Canberra Multicultural Forum and Capital Region Community Services. Additionally, HCCA shared an invitation to join the project directly with seven residential and aged care facilities in Canberra, Wards 11a and 11b at the Canberra Hospital, researchers and clinicians within the University of Canberra Centre for Excellence and Ageing, the

Capital Health Network and members of the Dementia Health Expert Network. HCCA also promoted the project at the 2024 Seniors Expo in September. The invitation outlined the aim of the project, eligibility criteria and what participants could expect when participating. All participants provided informed consent prior to enrolment in the study.

Data collection and analysis

Data for this project was collected through six semi-structured, one-on-one interviews. We spoke to five family carers of people with dementia and one person with dementia who lived in a residential aged care.

The interviews were conducted from July 2024 to October 2024 and were conducted by the members of the research team. Based on participant preference the interviews were conducted either in-person, via telephone or online via Microsoft Teams.

The conversations focused on:

- Health services accessed by the person with dementia
- How they access these services
- Support they receive to access services
- Experiences during planned hospital visits
- Experiences during unplanned hospital visits

Interviews were recorded and transcribed using a portable audio-only recording device or on Microsoft Teams. This was done with the participant's permission and in accordance with the privacy and confidentiality precautions indicated in the participant information and consent form.

NVivo™ software was used to analyse the transcripts and were categorised into themes. The interviews were coded in two rounds. The first round of coding was based on the predetermined codes that were guided by the research questions and to identify new themes or sub-themes from the transcripts. The predetermined codes were:

- Health services accessed;
- Access to care in residential aged care;
- Experiences of hospital care;
- Improvements to accessing care for people living in residential aged care.

The second round of coding identified themes around the involvement of family carers in supporting and managing health of people with dementia.

Limitations

This project is a qualitative study of the experiences of accessing care for people with dementia, and their families and carers, when living in a residential aged care. As such it is focussed on exploring participants thoughts, feelings, perceptions and experiences in-depth. Semi-structured conversations were conducted with six adults, five of whom were family members of a person with dementia. These findings should not be read as representative of the experience of all people with dementia and their families and carers in accessing care when living in a residential aged care.

A key limitation of this project is the low number of participants we were able to recruit. Despite extensive promotion and active recruitment of participants for this project, we found the project scope and participant eligibility criteria significantly constrained participant numbers.

Although the researchers spoke with family members who were interested in sharing their experiences, they were ultimately unable to participate because:

- Their family member did not live in a RAC in the ACT
- Their family member had not presented to the ED or needed hospitalisation in the previous two years
- Their family member was not living in a RAC, even though they had experienced BPSD and had presented to the ED

Recruitment for this project was limited by difficulties in engaging with families and informal carers of people with dementia living in RAC and the people with dementia themselves. The research team had discussions with eligible family members who chose not to share their experiences. The reasons for these included:

- Overwhelming carer responsibilities they faced for their family member with dementia as well as other family responsibilities
- Discussing their experiences while they were still going through them was too emotionally draining.
- Fear of reprisal. People with dementia are reliant on care from the RAC they reside in, and family carers are reliant on their family members being cared for. Despite the measures taken to ensure privacy, some participants were still unsure about participating due to the impact it may have on care.
- One person had a parent die shortly after they expressed interest in participating in the project and felt they were not able to contribute.

The findings of this project are primarily based on the experiences of family members of people living with dementia. It is necessary to note that the experiences of family members and carers are not the same as the experiences of people living with

dementia, who may have very different perspectives. Many family members and informal carers still play active and significant roles in supporting the care and wellbeing of people living in RAC and their insights are valuable. Our findings from these discussions can inform improvements in health care for people with dementia while reducing family/carer burden.

The final limitation to these findings is that only one participant in this project was a person with dementia who is living in residential aged care. As this project is focussed on experiences of accessing care when living in residential aged care for people with dementia and experiencing BPSD, this is a significant limitation to the findings of the project. However, the family participants indicated that many of the people with dementia began living in RACs as they began to require more intensive care. Family participants acknowledged that the person they cared for had limited ability to communicate, or didn't speak English to be able to contribute to the project.

Results

We conducted six interviews as part of this project. Five of the participants were family members of persons with dementia living in a residential aged care. One participant was an older person with dementia who is living in a residential aged care.

Transitioning to residential aged care

During the discussions, participants spoke around the circumstances and decisions that led to transitioning to residential aged care from living in the community. The decision to move into RACs for some participants was made by the person with dementia and their family members as they felt they couldn't live by themselves in the community anymore, for others it was a decision made by family carers as the healthcare needs or managing the behavioural changes of the person with dementia grew more difficult.

Access to health services when living in residential aged care

The people we spoke with most commonly accessed their GPs and geriatricians.

The health services 'provided' by the RAC included a GP, a geriatrician, and physiotherapists, podiatrists and masseuses. Healthcare access that was supported and provided by the RAC was welcomed by the family participants. The health services provided by the RAC eased the burden of care for many of the family participants. However, a lack of choice in who the GP may be meant some family participants chose to take their family member for healthcare appointments outside of the RAC. For one participant this was due to feeling like they were not listened to in the planning of the care for their family member and for another it was because their family member was still able to recognise her GP and enjoyed visiting them.

Additionally, family participants spoke about the role they played in supporting access to additional specialist care that was not regularly provided by the RAC. Some family participants organised access to this care through the RAC, others spoke about having to take their family member to see specialists like the optometrist, dentist and any additional GP visits themselves.

To support external access to healthcare for their family members, the family participants spoke about having to:

- let the RAC know in advance so they could print out care notes with relevant information for the appointments.
- manage their schedules around work and other caring responsibilities.
- ensure that they had access to appropriate transportation, as it isn't feasible to use public transport.

“Mum’s healthcare is a big deal because it’s not just make an appointment and take her to the appointment and take her back. It’s because I have to be completely aware of everything that could be relevant, because she can’t. She has no capacity to do it. And that’s when I’m managing her, myself, my husband has multiple disabilities, my children have disabilities and my grandchildren have disabilities” Participant A

Experiences during hospital visits

When we asked participants about hospital visits, family carers spoke about hospital visits across two categories: planned and unplanned admissions.

Planned admissions were pre-planned for appointments or surgeries and unplanned admissions were presentations to the Emergency Department which may be followed by an admission to the hospital.

Planned admissions

Participants who spoke of planned admissions identified that their family member had an overall positive experience of care during the admissions. For participants this was attributed to family carers being able to communicate the care needs of their family members prior to admission. Additionally, planned admissions allowed family carers an opportunity to choose the hospital, the specialists and surgeons.

One family participant spoke about identifying care needs during the pre-admission process to ensure that their family member had had positive experiences during their stay.

“So I flag it of course; because I complete all of the pre admission paperwork.”

Participant A

They described staff ensuring their family member was placed in a room across from the nurses' station and leaving the door open as long as they can to keep an eye on her and ensure she isn't distressed during her stay. As the participant highlighted, these accommodations were able to be supported due to their role in communicating care needs with hospital staff.

Unplanned admissions

In discussing unplanned admissions and presentations to the emergency department, family carers described positive experiences about the care provided by staff within the ED.

“I think ED do really well. Given when it comes to dementia informed practise, I would say ED does better, way better than say the optometrist or the dentist.” Participant A

Participants did however discuss the delays their family members experienced before being moved to an appropriate ward. Additionally, when discussing one particular unplanned admission, one family participant discussed the pressure placed on discharging as soon as possible to make room for more beds.

“The hospital was so keen to get rid of him because of the bed shortage. That was awful actually. Like he'd had a heart attack, a large one... and yet they turned around and said, 'look, he's got a nursing home, he'll get care. We have to move him on!'” Participant C

Discharge and transitions back to RAC

The transition from the hospital back to the RAC however proved to be more challenging. Family participants spoke about receiving mixed messages from the hospital staff around the discharge process. They also spoke about being the ones that needed to carry the information about the care that was provided at the hospital back to the RAC.

“So I think the care home was not involved in mum's care in hospital or what happens when mum is discharged from hospital. They had a place for my mum in the home, but they were not in any loop in the care and anything. They were just waiting on what we were going to do... Once she was discharged from the hospital, the hospital arranged for the ambulance and we went back to report.” Participant F

Role of families and carers in supporting access to healthcare

The discussions with all participants in this project have highlighted the significant role that families and informal carers play in supporting access to healthcare for older people with dementia even as they move into a residential aged care.

*“So we finally got him in and you kind of think that life would get better. But it didn't.”
Participant C*

As older people with dementia move into a RAC, the responsibilities of family carers in supporting access to healthcare does not end, rather the nature of the role they play evolves.

Family members were responsible for organising access to regular GPs and specialty care. For some family participants, this involved working with nursing staff at the RAC, to organise and pay for GPs or specialists to attend to their family members at the home. For other participants, family carers were responsible for organising and facilitating access to healthcare outside of the home. As discussed above, for some families the decision to support access to care outside of the RAC was due to a lack of choice in the healthcare provider or the added financial cost of facilitating access through the home was not feasible.

“That is over and above the standard fees and given that I've been paying half of her standard fees, and I have just had to stop work because my caring responsibilities are so high that I am no longer a reliable person in a workplace. I don't have the funds to pay for the staff to take her to the GP.” Participant A

Families who chose to support healthcare access externally to the RAC were responsible for collecting health information from nursing staff for the appointment, scheduling the appointment, organising transport and taking their family member to the appointments and back, debriefing and handing back over to the nursing staff and managing any follow up appointments or care.

Family participants talked about the logistical challenges they needed to consider when taking family members for appointments. These challenges were primarily around mobility, with some older people with dementia needing assistance to be lifted, requiring walkers to move around. Others struggled with their loved one's incontinence or the risk of absconding. They also discussed difficulties finding parking close to the doctors' offices.

“I can't take him anywhere because he's 110kg... I did take him to see the dentist two or three times because he had a toothache... But just getting him to and from there myself - because there's no ambulance to the dentist. Even disability parking is well away from the dentist. They have a lift, but unless they're able to deal with it...” Participant D

Family carers also played an advocacy role in supporting access to healthcare. Participants spoke about discussing healthcare needs with nursing staff to ensure they are aware of issues and are able to address them.

“...we need to tell them what she would need rather than – for example, if there is some tear in the skin or some bruise in the arm because she bumped somewhere, and if the carers see it, they might tell us. But if we need some help that it's not obvious to carers, but obviously mum is feeling uncomfortable, it's us to initiate what needs to be done.”

Participant F

This advocacy role continues during and after healthcare appointments with family carers being responsible for relaying health information to external healthcare services and providers and then reporting care/treatment plans and outcomes with nursing staff back at the RAC. This was particularly essential for participants whose family members are unable to communicate for themselves because of language or communication issues or they are not able to remember.

“I remember once actually the dentist was on phone with me, with a carer trying to tell me what my mum was trying to say. So sometimes the carer can interpret what my mum is saying, because...her verbal capabilities have also been highly impacted by the stroke. So sometimes when she says half of what she was trying to say, we try to interpret what the meaning is and it's complicated, it's complex.”

Participant F

Family carers also play an essential role in mitigating potential presentations to the ED. During the discussions, family participants identified that nursing staff at RAC would contact them as issues arose to identify next care steps. However, as described by one participant, the processes outlined by individual RACs impact how health issues are addressed.

“If something goes wrong, it's either a doctor issue or it's an ambulance issue. But the good thing about [residential aged care a], is they don't immediately call an ambulance because they've got registered nurses on staff. Whereas at [residential aged care b], they aren't authorised to even lift them off the floor. They can only stand there and say 'oh, you put your hand there!’”

Participant B

Only one family participant spoke of the Geriatric Rapid Acute Care Evaluation (GRACE) team visiting their family member following a collapse at the RAC. Other participants explained that they were the one who was contacted in situations as they arose. One participant described the role they played in supporting urgent access after surgery.

“I took her back to the nursing home and did the handover. [...]10 past six they rang me to say she's ripped her stitches out. I tried to take her in [the walk-in centre], because I thought they do stitches. And they said ‘we're not going to see her, we're gonna run out

of time, before we close'. So then I rang CALMS and got her a CALMS appointment. CALMS looked at it and went, '[I] can't restitch this. I'll tape it up and I'll bandage it in such a way that she can't access it. You need to go back to the surgeon'. So we were back at surgeon the next morning." Participant A

Person-centred care

When discussing access to care, participants also raised how care was delivered to people with dementia in a RAC. Nursing staff within RAC are required to ensure medications and medical aids are provided and taken/used by residents, however participants also spoke of the lack of flexibility in this approach. One family participant described having to advocate for their family member and reminding RAC nursing staff that their family member did not need to take certain medication if they chose not to.

"...of course there's a medication record and so the staff have to follow that. So when she says 'I don't want it', they say 'no, no, you gotta have it'. So I've had to have a few chats with them saying no, if she wants to refuse, she's totally entitled." Participant B

Our participant with dementia also spoke about their frustrations around being made to use hearing aids daily when they did not want to use it or needed to use it. As this participant explained,

"...the nurse was going to stand over me and make me wear them every day and I said no. I put my foot down and said I am not wearing them. They eventually realised and let me be, but I was about ready to take them out and stomp on them"

These experiences reflect a loss of patient-centredness when caring for older people with dementia in RAC, as it demonstrates an absence of choice when it comes to care unless individuals are able to advocate for themselves, or have someone to advocate for them.

Because individuals with dementia lose the ability to give consent and decisions must be made in consultation with family carers (with EPoA), the conversations with family participants also brought up concerns regarding choice and consent. These circumstances may give rise to conflict between the competent preferences or best interests of the person with dementia (or how their family interprets them) and the choices made by the person with dementia (who is now incapable of making decisions for themselves) or by their clinician. One participant described the challenges around the prescribing of behaviour modulating medication in the RAC.

"...he will be such a lonely old man sitting in a nursing home because he's so rude to the family when he's off the medication. It's just awful. And so what do you want? It's a ying

and yang thing. Do you want for him to be happier within himself? So there is this constant challenge where the nursing home constantly wants him to come off it. And I'm going absolutely no way. ...the private gerontologist is just so - ho hum - They go, 'Oh, whatever [my father] wants' ...it's not just one person. There's a whole family unit trying to kind of keep all the balls up in the air." Participant C

Observations

The interview with the person with dementia was conducted in their RAC by the lead researcher. The participant was living in a secured dementia ward with other older people with dementia.

The participant reported being in good health and not needing a doctor very often. The participant has a regular community-based GP, however the participant explained that they had not seen the GP in a little while as they were in good health and their daughter who facilitated the visits has been away. The participant reported that they enjoyed walking during the day to stay active and mobile as it also helped with their knee pain.

During the interview the researcher made the following observations:

- The participant was quite active and enjoyed walking and moving around throughout the day. However, as the participant was in a secured wing, they were only able to walk up and down one singular hallway all day.
- The participant was still very conversational and enjoyed reading and being social. In contrast the other residents that were observed on the day were not as conversational or active or able to communicate.
- The participant would get quite frustrated by the other residents in the ward. This was shown when the conversation would be interrupted by other residents making noise outside the room or trying to converse with them or the researcher during the interview.

These observations reflect the findings in a scoping review into the self-reported needs and experiences of people with dementia who lived in RACs¹⁰. The review identified that people with dementia wanted freedom and choice and control of their daily routines. The review also identified the challenges with developing and maintaining relationships for people with dementia in RACs, as residents expressed feeling frustrated by other residents who may be noisy or disruptive.

Research into the relationship between BPSD and the needs of older people with dementia in nursing homes has identified that the needs around company, daytime activities and psychological distress were most of reported as not being met¹¹. The

study also found that these unmet needs were positively correlated with the number of BPSD.

Consistent with the researcher's observations and research, a family participant also spoke of the decline of their family member during lockdowns.

"The deprivation of activity and access with other people, she deteriorated rapidly during the first lockdown. She went from being quite independent to ringing me up because she couldn't find her glasses and getting lost driving and that sort of stuff. She decided that it was time to move into aged care." Participant A

Opportunities for supporting care for people with dementia

When asking family participants about what could be improved to support access to health care for their family member when in hospital, they responded:

Continuing supports offered in the community to RACs

One participant spoke about the lack of supports available to families and informal carers once the person they care for enters a RAC. The interviews highlighted that RACs do not provide transportation to external appointments, or access to additional care unless they are paid for by the family, a cost that some families cannot afford.

"But because she's in care, it's all - like the financial, physical transportation, it's all on me. Because she's in care, there's no support. And that sucks." Participant A

This participant spoke of being able to access taxi vouchers to help take their family member to appointments when they lived in the community. Having access to similar vouchers and supports would reduce significant burden in supporting access to care.

Some participants also spoke of the support and services provided by the Canberra Health Services Rapid Access of the Deteriorating Aged at Risk (RADAR) team in supporting them and their family member while they lived in the community. The doctors within the RADAR service were able to provide a diagnosis and treatment options for their family member. However, once individuals enter a RAC, older people and their families are no longer able to access the valuable supports provided by these services and are required to engage health service providers privately.

"I find it very challenging with the [private] gerontologist because they just take a really light touch to everything. But the RADAR one, he visited us in the home, and he saw the struggle I was under." Participant C

Supports to navigate the aged care system

Family participants also spoke about difficulties with navigating the aged care system to be able to support their family members. They spoke of difficulties in finding information on ACAT assessments, and the wider aged care system and services, and the challenge this added when trying to navigate the aged care system while supporting someone else.

“I have to say for the last 18 months of my life, it's been pretty awful, incredibly challenging and I have a huge amount of knowledge of aged care, and you'd think I'd be able to access all these services and connect all the dots. Hell no, you know.”

Participant C

Family participants described learning about services and supports and information on ACAT assessments through social workers and nursing staff in the hospital, one participant spoke about working with a private consultant who helped them to navigate the aged care system and provide support and advise services and supports that are available and how to access them.

“So she's a just a little private, aged care consultancy person. She was very good. So I've recommended her to other people. She's basically a resource. [to go to] 'What do we do? How does the system work?' And my sense is that outside of the hospital system, it is hard to find that out [...] - Or people don't seem to really understand how to navigate it.” Participant B

Participants identified that information on aged care services and supports should be made available and offered to people well before they need it to increase awareness and preparedness for navigating the system.

Next steps and considerations

The aims of this project were to identify how older people with dementia accessed care when living in residential aged care. This project also sought to understand the care experiences of these older adults within the hospital setting. The considerable challenges we encountered in recruiting participants for this project highlight some key considerations when planning future projects and in designing supports and services for people with dementia and their families.

People with dementia may have considerable difficulties with communicating or being able to report on their experiences accurately as a result of their conditions. Engaging with families is also challenging due to the demands placed on them by their caring responsibilities or their emotional distress. Families and informal carers are required to manage their own lives and health, manage and support their family member with dementia living in a RAC and may often have other familial caring responsibilities. The caring role places intensive demands on their physical, and emotional capacity and

often taking time to participate in research activities such as this can be beyond their capacity.

The royal commission into aged care highlighted, that while over 50% of people living in residential aged care have a diagnosis of dementia, the quality of care provided for people with dementia in aged care needs significant improvement. As dementia care is core business for aged care services, the key recommendations made in the royal commission for aged care services included⁶:

- Providing mandatory dementia training in residential aged care and in care at home
- Ensuring having the correct number and mix of staff trained in dementia care
- Having the right physical environment
- Having the right model of care
- Use of the Specialist Dementia Care Program to support people exhibiting severe BPSD who are unable to be cared for in mainstream aged care services.
- A review of the Australian Aged Care Quality Standards to define quality aged care.

Improving access to care while living in the community

When considering how best to support older people with dementia while living in a RAC, it is important to consider the reason they are now living in a RAC. For all our family participants, the choice to move into a RAC was either made by the older person themselves or together with the family as their care needs grew more intensive or managing BPSD became more challenging. These reasons align with existing research which highlight that increasing distress as a result of BPSD and burden of care placed on family carers increase the likelihood of admissions to nursing homes for people with dementia¹². Furthermore, a 2022 study compared BPSD and caregiver distress between older people with dementia living in the community and living in nursing homes⁴. The study identified that older people with dementia living in the community experienced more clinically significant BPSD and caused more severe distress to carers than those living in nursing homes.

The Australian Royal Commission into Aged Care identified that while most older people want to continue living in their own homes, the challenges of being able to access care at home can contribute to moving into residential aged care earlier than they would like⁶. Access to care at home is often limited by the lengthy waits for an assessment to access home care supports or when finally able to access supports some may receive less care than they need or may not have access to the services they need because of where they live. These challenges compounded with inadequate

quality respite care increase the risks of preventable hospitalisations, carer burnout, declining health and abilities and early entry into residential aged care⁶.

These findings highlight the need to improve access to dementia supports and care that is provided in the community to allow people to live at home longer.

Improving access to care in residential aged care

While RAC do provide access to healthcare such as GPs, geriatricians, physiotherapists, and podiatrists; the care required by people with dementia is not limited to these specialities and the responsibility of supporting access to other speciality care for residents with dementia lies with their families and carers.

As identified by the royal commission into aged care, less than a third of people living in residential aged care see a specialist in a year compared to the greater than two-thirds of older people living in the community⁶. This has been attributed to the limited ability of older people in RAC to be able to go and see a specialist, and a reduction in the number of specialists who visit RACs or take on new patients who enter the RAC. Additionally, current funding schemes and benefits do not provide adequate incentives to support coordinated care from health professionals to provide care to older people where they live.

Our discussions with family participants have highlighted that the considerable additional cost and/or the lack of choice in the healthcare professional that provides care within the RAC drives some family members to continue to facilitate access to healthcare outside of the RAC themselves. Family participants spoke of the value of publicly available services such as RADAR and community financial supports for things like transportation to and from medical appointments while their family members lived in the community. As older people move into a RAC setting, publicly available services and supports fall away and place additional financial and logistical burdens on family carers. For our participants, extending such supports to be available as people move into RAC would help to support access and reduce carer burden.

Improving supports for families and informal carers

Family carers have a role in supporting access to healthcare as well as in maintaining good health and ensuring positive healthcare experiences. Our participants played a role in monitoring the health and wellbeing of their family member during visits (such as being present at meal times to feed their family members), coordinating with RAC nursing staff to manage and organise additional care where needed, taking family members outside of the RAC to access care, supporting handovers back to nursing staff following appointments and hospital admissions and managing safety and appropriate care during admissions. These findings are consistent with research exploring the roles

of family carers in managing and supporting access to quality care, where family carers took on roles in detecting changes in health within RACs¹³ and played active roles in hospital settings to ensure patient safety and delivery of appropriate care¹⁴. The consistency in findings support a need to formally recognise the valuable roles played by family carers in supporting healthcare. However, it is necessary to acknowledge that these responsibilities are taken on only by family carers who are willing and able to do so.

The active roles taken by our family participants in supporting healthcare access and managing health can play a part in reducing potentially avoidable ED presentations. Our participants spoke of paying attention to health changes during visits or being the decision maker on what to do after incidents occur at the RAC. The decision on whether or not to call an ambulance can sometimes fall on the family carer, however the procedures outlined within the RAC have a more significant impact. While only one participant spoke of the GRACE team being engaged for their family member at the RAC, research has shown that programs that enable nursing staff within RAC to seek clinical advice for residents, particularly after-hours, helps to reduce ED presentations¹⁵.

These findings reinforce the need to implement the recommendations made within the royal commission into aged care around supporting training for staff in dementia care, as well as ensuring enough staff are available to provide care for people. However, these findings also raise concerns about the quality of care being provided to older people with dementia in residential aged care, particularly a

Managing choice and consent

However, family carers discussed the challenges of providing care, including the potential for conflict as dementia patients lose their ability to give consent and the need to base decisions about care and treatment on the preferences of the patient, their family, their formal carers, and clinicians. For some participants this issue was faced around medication or use of medical aides to support daily activity, for others it was around treatment decisions for acute or chronic co-morbid health issues. These challenges are consistent with those observed in existing literature.

A 2021 systematic review¹⁶ exploring the relationships between people living with dementia, their family carers and health professionals, identified that a person with dementia and their family carers have an existing relationship and that health professionals can have key impacts on these relationships. The study identifies that for a person with dementia to be an active participant in their care, health professionals also need to understand the impacts of the care they provide on the person with dementia and their family carers, as well as on themselves.

The participants in this project reported a range of experiences in accessing or supporting access to healthcare. Supporting access to healthcare for older people with dementia is challenging when having to navigate a complex aged care system, managing physical, emotional and financial needs of the person with dementia, as well as managing their own life and additional caring responsibilities. The findings of this research have highlighted the need to expand publicly available services for people with dementia and their carers to provide ongoing support as and after they enter RACs. This recommendation goes beyond the scope of those made within the royal commission into aged care, which had a focus on improving how carers are able to access information and subsequent care and services⁶. Importantly, the findings of this report highlight the complexity of providing care for people with dementia, and the challenge that remains to be addressed by health services and health professionals is in supporting the needs of both the person with dementia and the needs of their families and carers.

While the findings of this study highlight some key areas of improvement for providing care for people with dementia in residential aged care, it is important to note that these findings have been based on people with dementia who have family members playing an active role in supporting their health and wellbeing. While some older people with dementia have family members or other informal supports to support access to care and advocate for them, there are many who do not have supports or have supports who are able to be as actively engaged. It is critical to ensure that advocates are made available in residential aged care for older people for those who do not have informal carers providing active care and support.

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