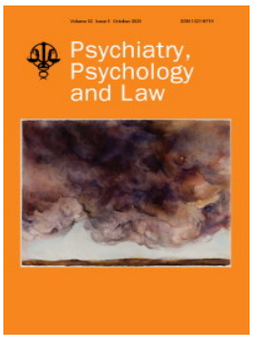

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# Behavioural changes and perceived criminal offending: an exploratory study of accounts from carers of people living with dementia

Nola Ries[a] and Fiona Kumfor[b]

[a]*Faculty of Law, University of Technology Sydney (UTS), Australia;* [b]*School of Psychology and Brain & Mind Centre, University of Sydney, Australia*

Many people with dementia, especially those with younger age of onset and frontotemporal dementia, experience changes in behaviour and personality, including disinhibition, socially inappropriate behaviour and aggression. These behaviours can lead to contact with law enforcement personnel where there are criminal offending concerns. To date, little research has explored carers' experiences of such situations. This article reports on an exploratory interview study, conducted in Australia, with nine carers of people with dementia and two people living with a diagnosis. The study revealed behaviours that posed risks of harm, including verbal abuse, physical aggression, alleged shoplifting, unsafe driving and public behaviours perceived as odd or threatening. Responses included limiting the social participation of the person with dementia, bans on attending community venues, detention by police/security and, in some cases, charges. Carers offered suggestions for how behaviours and anti-therapeutic responses could be prevented through improved education and supports.

**Keywords:** aggression; behavioural and psychological symptoms of dementia; carers; changed behaviours; criminal offending; dementia; disinhibition; frontotemporal dementia; police; younger onset dementia.

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## 1. Introduction

Many people with dementia, especially those with younger age of onset, experience changes in behaviour and personality, including disinhibition, socially inappropriate behaviour, aggression and changes in judgement and reasoning.[1] These behaviours can lead to contact with law enforcement personnel where there are criminal offending or public safety concerns.[2] A developing body of research in countries such as the United States,[3] Sweden[4] and Japan[5] investigates criminal offending in dementia, linking executive dysfunction to impulsive violent or anti-social acts. These behaviours are of particular concern in frontotemporal dementia (FTD);[6] one-third to one-half of people with FTD exhibit behaviours that may raise allegations of physical and verbal abuse, theft, hazardous driving and inappropriate sexual conduct.[7]

Recent research on dementia and offending has examined criminal prosecutions and dispositions.[8] It is increasingly recognised that criminalisation of behavioural symptoms of dementia is unjust. Accused persons with dementia who cannot be held legally culpable due to brain pathology[9] should be diverted

Correspondence: Nola Ries, Faculty of Law, University of Technology Sydney, PO Box 123, Broadway, Sydney, NSW 2007, Australia. Phone: +61 (02) 9514 3156. Email: Nola.Ries@uts.edu.au

from criminal punishment and receive appropriate care and support.[10]

Dementia-related behaviours have also been investigated in the context of spousal and family caregiving.[11] An Australian study that involved 71 families of people diagnosed with younger onset dementia found that over 90% of family carers reported 'difficult-to-manage' behaviours, including aggression, disinhibition and inappropriate social behaviour.[12] A UK study of over 200 family carers found that nearly half (47%) reported experiencing recent abusive behaviour from the person with dementia.[13] Other studies of family carers have reported that at least one-quarter experience physical violence in providing care for their relative with dementia.[14] Aggressive and disinhibited behaviours contribute to increased carer stress.[15] Carers express fear and shame about such behaviours,[16] and they worry about unaccompanied out-of-home activities by the person with dementia.[17] Some studies with carers have anecdotally reported incidents that led to police involvement,[18] however, scant qualitative research has explored carers' experiences of such situations. The perspectives of people with dementia is even more limited in research, as insight into wrongdoing and awareness of harm to others may be limited, especially in FTD.[19]

More research is needed to understand the early course of these behaviours, how they manifest in home and community settings, the situations that lead to contact with the police or other authorities and strategies to reduce the risks of harm for people living with dementia, carers and community members. The present study, conducted in Australia, aimed to explore carers' accounts of potential offending behaviour by a community-dwelling person with dementia, including situations that involved contact with police or security personnel. The study was considered exploratory given the dearth of Australian research on the topic and the limited overseas research.

## 2. Method

### *2.1. Study design*

The research was designed as a qualitative descriptive study, an approach suited to investigating a phenomenon, experiences and perspectives 'from the viewpoint of the participants',[20] with findings presented in a way that stays close to participants' own descriptions. The research was approved by the University of Technology Sydney Human Research Ethics Committee (HREC Approval No. ETH22-7190).

### *2.2. Participants and recruitment*

Participants were recruited via a dementia research clinic at the University of Sydney, which sees people from across Australia and specialises in frontotemporal and younger onset dementia. Eligible individuals were carers and people with dementia who had previously completed the Misdemeanours and Transgressions Screener, a questionnaire on criminal offending in dementia.[21] The questionnaire asked about potential offending behaviours, such as: traffic violations (eg. driving without a licence); not paying for something (eg. an item in a shop, a restaurant meal); verbal or physical altercations; entering property without permission or damaging property; and behaving towards someone in a way that was unwelcome (eg. unwanted hug). The questionnaire also asked whether any such behaviour led to contact with police or authority figures such as security personnel.

A clinical psychologist employed by the research clinic, who was not part of this study team, emailed a letter of invitation to carers who had reported relevant behaviours. Priority was given to participants who had reported behaviour leading to, or more likely to lead to, interactions with police or security personnel, with efforts to ensure demographic diversity. Individuals interested in taking part in an interview contacted the research team directly or authorised the clinic staff member to share

their contact details with a member of the study team. Our study design included the option of dyad participation to hear from the carer as well as the person living with dementia. All participants gave written informed consent to participate.

### 2.3. Data collection

Semi-structured interviews explored: behaviours and situations that led to problems or disputes; elaboration on situations considered to be more serious, including those that led to interactions with police or security personnel; responses to the behaviours and outcomes of the situations; what could have been done better, especially in terms of police/security responses; and suggestions for how behaviours and the risk of contact with police could be prevented for people living with dementia. Demographic questions asked about gender, age and duration of caring role.

Interviews were conducted via web conference (Zoom) to support convenient participation for individuals at varying locations. All participants were able to consent to participate in the study and complete an interview in English. Interviews were conducted by either a lead investigator or a research assistant with legal qualifications and experience conducting interviews with people with lived experience of dementia. Interviews were conducted between August 2022 and July 2023 and averaged around one hour (ranging from 48 to 84 minutes). Interviews were recorded with participant consent, and audio files were professionally transcribed. Participants were offered the option of reviewing transcripts of their interviews to clarify statements and provide further information to the study team. No participants chose to review and provide such feedback.

Based on guidance on achieving 'information power' in qualitative research[22] and recommendations for key informant studies,[23] it was anticipated that 8–10 participants would provide adequate data. Relevant considerations were that this was an exploratory study on a focused topic (ie 'offending' behaviours among people with dementia living in the community), and data collection involved key informants with direct knowledge on the topic from lived personal experience.

### 2.4. Data analysis

The first author led the data analysis. All transcripts were read in detail to gain familiarity with the data. Transcripts were then re-read to summarise data on the behaviours, responses and impacts and to extract and group quotations. Both authors reviewed, discussed and agreed on the presentation of the data, including the selection of quotations that illustrated participants' experiences. Quotations were edited to tidy oral speech while retaining authenticity.[24] Quotations appear in the main text and an additional file (supplementary material).

## 3. Results

### 3.1. Overview of carers and their accounts

Nine carers took part in in-depth interviews. The people cared for were spouses or parents, most of whom had younger onset frontotemporal dementia. Their years of caring experience ranged from 3 to 10 years (average of 6 years). Most lived in urban communities. Participant profiles, the behaviours they described and responses to those behaviours are summarised in Table 1, with further detail presented below.

### 3.2. Reported behavioural changes

Carers described changes in behaviour that were out of character for their spouse or parent, which were apparent prior to formal diagnosis (see summary in Table 1 and illustrative quotations in supplementary material). These behaviours occurred in public settings, such as shops, social venues and workplaces, and in

Table 1. Carers' profiles and accounts of behaviours and responses.

| | Carer profile | Person cared for | Reported behaviours of person with dementia | Responses to behaviours |
|---|---|---|---|---|
| Carer 1 | Female<br>54 years | Husband<br>Younger onset dementia | Aggressive behaviour in public places (eg throwing items in shops; verbal aggression to staff) | Being watched and followed by store manager and security personnel; threats to call police; staff refusing to serve carer and her husband and making unkind remarks about husband |
| Carer 2 | Female<br>68 years | Husband<br>Younger onset dementia (FTD) | Shoplifting, gambling, stealing money to gamble, verbal aggression, driving violations (eg driving after licence cancelled) | Carer restricted access to money and spoke to shopkeepers, bank and police to advise of husband's diagnosis; placed tracker device on husband and followed him; hid car keys<br>Security personnel and police were called for shoplifting incidents; person with dementia handcuffed and detained |
| Carer 3 | Female<br>61 years | Husband<br>FTD | Verbal and physical aggression towards wife; paranoia | Police involvement led to domestic violence charges and apprehended violence order (AVO) against husband<br>Involuntary mental health admission to hospital |
| Carer 4 | Female<br>27 years | Mother<br>Younger onset dementia (FTD) | Extreme verbal abuse to strangers; new gambling behaviour | Involvement by security personnel and police; bans on attending community venues |
| Carer 5 | Female<br>49 years | Mother<br>Younger onset dementia (FTD) | Social disinhibition; approaching children; public urination; trespassing on neighbours' property | Carer spoke with security staff and neighbours about her mother's diagnosis<br>Threat by neighbour to contact police |
| Carer 6 | Female<br>62 years | Husband<br>Younger onset dementia (FTD) | Taking items without payment, risky driving, 'wandering' | Carer monitored activities; stopped access to driving; contacted police to advise of husband's 'wandering' |

(*Continued*)

Table 1. (*Continued*).

| | Carer profile | Person cared for | Reported behaviours of person with dementia | Responses to behaviours |
|---|---|---|---|---|
| Carer 7 | Female<br>59 years | Husband<br>Younger onset dementia (Alzheimer's disease) | Verbal and physical aggression towards wife; unsafe actions in workplace, unnecessary shopping; dangerous driving | Medical retirement from employment<br>Carer's responses to husband's behaviour focused on self-protection (eg locking herself inside a room in their house) |
| Carer 8 | Male<br>75 years | Wife<br>FTD | Rude behaviours at work; shoplifting; driving violations | Termination of employment; police involvement for repeated shoplifting; bans from stores<br>Carer 'blew up' at wife due to repeated shoplifting |
| Carer 9 | Male<br>32 years | Father<br>Younger onset dementia (FTD) | Obsessive behaviours, suspicion of others, social disinhibition; risky driving | Carer intervened to halt disinhibited behaviours; removed access to vehicle; sought residential care placement for father |

the home. Carers reported situations such as the person becoming short-tempered and aggressive, sometimes in the context of frustrating situations with other people, or having 'paranoid' or 'obsessive' thoughts, which in some instances were exacerbated by alcohol use:

> He got really nasty [verbally] because … he was paranoid that I was ripping him off for all his money. (Carer 7)

Disinhibited behaviours included inappropriate and offensive language in public settings, in some instances involving uncharacteristic racism:

> He [father] essentially didn't like people with beards … when he saw someone with a beard or someone wearing a Muslim hijab he would [say] … we've got to get away, I don't like him. Yes, I don't know where that came from because my father was never racist at all. (Carer 9)

> She [mother with dementia] was becoming so racist and so rude towards people, verbally. … Some of the remarks you would never say to your worst enemy. It was pretty disgusting. (Carer 4)

Disinhibition also involved approaching strangers, sometimes children, and trying to touch them, striking up odd conversations or making faces. One man said his wife developed 'a lack of impulse control. So, when she becomes obsessed with doing something, she will just do it regardless of the consequences' (Carer 8).

Repeated shoplifting led to contact with security guards and police. Gambling-related behaviours in social venues caused concern for several carers, especially when new or increased gambling led to conflict about access

to money and exposed the person with dementia to risky situations in public betting outlets.

Many carers reported unsafe driving behaviour that led to restriction or cancellation of licences, sometimes after police involvement. To reduce risks, carers hid car keys, removed the car or contacted police to alert them that a spouse with dementia was driving unlawfully without licence. The resulting loss of independence led to new difficulties:

> When she lost access to her vehicle, she would hitchhike, but rather than hitchhike on the side of the road, she'd walk down the middle of the road to force people to stop to pick her up, which is quite dangerous. (Carer 8)

> When I took the car away he was out every day trying to look for the car and then ended up getting lost in the streets. (Carer 9)

The changes in behaviour eventually prompted medical investigation and a dementia diagnosis.

### *3.3. Responses to behaviours*

#### *3.3.1. Carers' responses*

Carers monitored the person with dementia, such as tracking them via a device (eg phone, watch), physically following them, accompanying them or limiting access to venues where behaviours such as shoplifting or gambling were a concern. Carers also proactively spoke with staff at venues the person frequented to advise them of the dementia diagnosis and to provide the carer's contact details in the event of problems. Carers also intervened to prevent behaviours, defuse situations and make amends, such as returning or paying for shoplifted items:

'It was basically watching him [husband with dementia] … making sure he was under supervision. … I was following him most places' due to incidents in local shops and venues (Carer 2).

'He wasn't allowed to go to McDonald's unless I went with him' to stop him from taking items, eg newspapers for customers (Carer 6). '

I'm constantly looking for ways to defuse the potential for behaviours' (Carer 3).

Carers had to balance risks:

> We had to work out all sorts of ways of caring for him [husband] and making sure that he could be free to do what he wanted [in the community]. He wasn't too constrained. I didn't want to lock him up [referring to placement in residential care], not until it was absolutely necessary. (Carer 2)

> It felt like I was taking over in control of so much of his life [by restricting activities], and, you know, I didn't have confidence in him. So, it really kind of affected our relationship. Our relationship became very tense and stressed, and lots of arguments over it. (Carer 7)

#### *3.3.2. Responses by others*

Carers described responses to the person with dementia in community settings, including by members of the public and by authority figures such as police, security personnel and managers of commercial venues. Prior to a diagnosis, carers lacked knowledge to advocate on behalf of the person with dementia. Following diagnosis, carers tried to intervene and advocate, but found this difficult when the person did not fit the typical stereotype of dementia:

> I tried explaining this to security guards … she's got dementia, this is something that can happen, it can get quite aggressive. And they said, no, she's too young, she doesn't have dementia, she's just rude. So, it was really hard for me to explain it to people. (Carer 4)

Negative responses from people in public spaces included shop staff not wanting to interact with the person and hostility between the person with dementia and people they

encountered. Carers worried about risks to the person with dementia:

> There were risks like … every time she left the house, I thought that was a big risk. … Every time she left the house it was stressful for me because I thought that she was going to get attacked or punched or hit. (Carer 4)

> I am worried that someday somebody's just going to push her … especially in a club if people have been drinking – my worry is more about that. That somebody might attack her or push her. And she's only tiny. (Carer 5)

### *3.3.3. Bans from community venues*

People with dementia were banned from local shops or social venues due to verbally abusive or disruptive behaviours and shoplifting. Carers had mixed views; bans avoided risks for community members and the person with dementia, but also limited their social participation:

> As much as I didn't want her to be banned and I wanted her to have freedom, I think at that point in the diagnosis it was almost like if she wasn't banned, something bad could have happened … if she kept going to the shop every day alone and abusing random people. (Carer 4)

One carer described his spouse's repeated shoplifting, which led to her being banned from a local supermarket. He felt that store management handled the situation appropriately:

> I think they dealt with it reasonably sympathetically. Obviously they can't have people coming in and stealing stuff out of their store. When [my wife] became known and there'd been several instances of these things, they had to contact the police. … I went and spoke to the manager there on a couple of occasions and he was perfectly reasonable. He just said, well, I can't allow this to go on … it got to the point where the regular staff in there recognised [my wife] when she went in and they would just call up to the security person and just escort her out of the store. (Carer 8)

### *3.3.4. Interactions with police*

Carers described police involvement in various ways, including police being called by local shops and clubs due to 'suspicious' or aggressive behaviour by the person with dementia, police following and questioning the person with dementia, police attending a home due to a call for neighbour disputes or a domestic assault and, in some cases, arrest and laying criminal charges.

Carers described concerns about police involvement:

> Police were involved on quite a few occasions … because of this neighbour who had called the police on her [mother with dementia]. And the police even knew the situation. They knew my mum had dementia. … But, still, they had no real sympathy. … I think the police maybe could have understood our situation a little bit better. (Carer 4)

> He [husband] was shoplifting … and this … shop [employee] tried to physically stop him and he grabbed him. … And then they called the police and the security, the shopping centre security. … [He was taken to] a back room, in handcuffs and with the police and the store security. … He was very distressed and he was traumatised for days. (Carer 2)

> Any time the police were involved was atrocious. In their minds it was domestic violence and they got very aggressive toward him [person with dementia] as the aggressor. They cuffed him. … Sometimes it is domestic violence but because the person is impaired [by underlying disease] we've got to figure out how to deflate that situation. (Carer 3)

Carers appealed to police not to pursue actions against the person with dementia, which

avoided charges or resulted in a withdrawal of criminal proceedings:

> [T]he police came and spoke to me [about wife's repeated shoplifting]. I explained to them what the situation was [with her dementia] and they moved on with something that they felt was probably a bit more serious. So, they didn't take a heavy-handed attitude to it at all. (Carer 8)

> I gave them [police] some paperwork and reports from [specialist clinic], from her doctors and her neurologists at the time. And they basically said, yes, we need to drop this, because it seems like she really had no intention of actually verbally abusing, and she couldn't have stopped herself from doing that. So, they dropped all the charges in the end. And we didn't have to go to court, which was a saviour. But that was quite a stressful time, for sure. (Carer 4)

Several carers contacted the police on their own initiative. For example, a carer who worried their spouse would be stopped for shoplifting proactively notified the police. Another asked police to apprehend a person with dementia who was driving after their licence had been medically cancelled. One carer even self-reported to police after assaulting his wife: 'She wasn't physically hurt but it was by law an assault. … It was just a spur of the moment thing where I just lost it [in response to behaviours]' (Carer 8).

Carers also commented on factors that protected a person with dementia from police involvement. Two carers noted the small stature of their parent with dementia, which may have made their odd public behaviours less likely to be perceived as threatening. Another carer experienced verbal and physical aggression when her husband consumed alcohol to excess, but felt she could protect herself: 'I could knock him over with a feather … [when] he's staggering everywhere [and] he doesn't have too much strength to overpower me' (Carer 7). She noted she would call police if she felt at greater risk of harm.

### *3.4. Carers' suggestions to reduce risks*

#### *3.4.1. Improve awareness and understanding of dementia and behavioural symptoms*

According to carers, there is a need for better community awareness of different types of dementia and behavioural symptoms, especially for FTD and younger onset dementia. Carers described their own efforts to educate others:

> I've spoken to heaps of people over the past few years trying to get the message out there. Some people have never heard of FTD. When they see someone behaving strangely like mum does sometimes, they don't understand that it might be dementia. (Carer 5)

Another carer devised an information sheet with her husband's name and photo that explained: 'I've got a condition called frontotemporal dementia and basically I take things that are not mine and I don't pay for them. Please contact my wife'. (Carer 2)

#### *3.4.2. Training for police, medical and legal professionals*

Carers advocated for better police training about dementia, particularly in relation to behavioural symptoms, younger onset dementia and de-escalation strategies for aggressive or violent behaviours. 'But whatever way that they're [police] taught to identify dementia, it's probably more like forgetful people with Alzheimer's that have forgotten to pay at the checkout. It's not somebody who has frontotemporal dementia' (Carer 2).

A carer who had multiple interactions with police due to his wife's behaviour, which included repeated shoplifting and driving violations, felt it was unrealistic to expect police to have detailed knowledge about less common forms of dementia, such as FTD: 'I think they [police] should be made aware that these things exist in society, in the community, but you can't expect them to have a detailed understanding of all that. I think that's just unreasonable' (Carer 8).

Carers described knowledge gaps about dementia among medical and legal professionals. Diagnostic delay was a problem in the context of younger onset dementia; diagnosis gave carers knowledge of how to support their spouse or parent and reduce risks of behaviours escalating to serious problems:

> I haven't met a GP yet who understands these different dementias. If it's not a memory issue and they can think Alzheimer's, they just don't think dementia. (Carer 3)

> Some GPs still don't recognise the symptoms of frontotemporal dementia and don't [refer the patient] on to somebody who might know. (Carer 2)

> My dad getting involved in legal problems, that's probably an area that's sort of like a bit of a black hole. … [From the lawyers] it was sort of like, your father has dementia, okay. And they were, what was his capacity? And it's, well, he's got a behavioural variant. And it was in their world it's dementia and memory loss. And it's the predominant feature was that his behaviour was changing. … Perhaps there could've been some education in the legal world as far as dementia not just being memory loss, but changes in behaviour. (Carer 9)

#### *3.4.3. Support for person with dementia and carers*

Paid workers who supported the person with dementia to take part in community activities mitigated risks by improving mood, providing positive interactions and reducing episodes of aggressive behaviour. As one carer stated:

> [Mum] started seeing them [paid carers] as friends and they'd go out for coffees and walks, and I think that really changed her mindset. And she had people to socialise with, so it's her being part of the community in that sense, and having carers come and visit her and see her and have something to do every day, that gave her a lot of value, I think, in her life again. So, that's when we really started seeing some positive changes. (Carer 4)

Support workers also provided respite for carers. Carers also identified a need for urgent support, such as during or in the immediate aftermath of an episode of violence by the person with dementia. A national dementia support helpline was noted as a valuable service for guidance on behavioural symptoms and modification strategies. In contrast, a carer who contacted a gambling helpline due to concerns about her husband with dementia was disappointed: 'They didn't have a clue' (Carer 2). Carers found valuable information and connection through dementia support groups, where they could discuss and share experiences about behavioural concerns. Carers also called for better respite and accommodation options for people with behavioural symptoms and younger onset dementia.

### *3.5. Perspectives of people with dementia*

Participation of people with dementia was limited due to disease progression, moving to residential care and, in two cases, the death of the person with dementia.

Interviews were conducted with two people diagnosed with FTD, one female and one male. The woman, aged 69 years, was described by her carer as being socially disinhibited, leading to contact with security personnel and threatening responses from neighbours. In her own interview (with the carer present but not speaking) the woman described activities she enjoyed, such as going for walks and attending a social club for games and dancing. She described her interactions with other people in positive terms. When asked whether anyone had reacted to her like she had done something wrong, she said no. She said she never had arguments with neighbours.

A man, aged 76 years, participated in an interview on his own. He described a positive outlook on life and a sense of meaning and contribution from his involvement in

community volunteer initiatives, such as fundraising for children with cancer. He described one recent situation of a police officer giving him a ticket for parking in a no-parking zone and a verbal disagreement with the officer. This incident was not described in a way that implicated his dementia diagnosis, and he purportedly had a valid licence.

The generally positive tone of these interviews aligns with previous studies that found that people with FTD 'exaggerated positive qualities and minimised negative qualities'.[25] An interview study with seven people living with a diagnosis of FTD also found that all participants emphasised having a positive outlook,[26] and concerns about behavioural changes were raised by carers rather than the person with the diagnosis.

## 4. Discussion

The behavioural symptoms of dementia explored in this study provide new insights on risk considerations and carers' experiences when behavioural changes involve contact with police and security personnel. The findings highlight that reducing the risk of harm to others may paradoxically result in harm to the dignity and autonomy of the person living with dementia.

### *4.1. Other-regarding risks and reducing risks of anti-therapeutic responses*

Existing literature on risk and dementia has focused primarily on risks to self for the person with dementia, such as critical wandering and the risk of getting lost,[27] risks to personal safety in the home and self-neglect.[28] It is recognised that 'there is inevitably a level of risk associated with having dementia and living in the community … caregivers and professionals have to accept that, albeit infrequently, the person with [dementia] will be in danger'.[29] Tolerating a degree of risk to self is an aspect of the dignity of risk for people living with dementia.[30]

This study has shed light on situations where the behavioural symptoms of dementia pose risks to others, since they may threaten or harm family carers and people in the community. It is important to mitigate known risks and avoid escalation to crisis situations. However, measures to reduce risks to others may have consequential risks for the person living with dementia.

As Fieldhouse and others noted in a Dutch study involving carers of people with FTD, behavioural symptoms can be 'easily misinterpreted by the patient's surroundings and society' and trigger 'intervention by law enforcement'.[31] These include risks of negative responses by others, including community members who feel threatened or affronted and law enforcement personnel with the power to detain, arrest and charge. In extreme cases, police may respond with excessive use of force.[32] Carers' responses may also be anti-therapeutic, to the extent that they unduly constrain the activities and social participation of the person with dementia. In the following sections we consider avenues to minimise the negative impact of behavioural change to the person with dementia and the community more broadly.

### *4.2. Earlier diagnosis*

In Australia, the average time lag between the onset of symptoms and a dementia diagnosis is around three years, but can be as long as five years for people with younger onset and atypical dementia syndromes.[33] More timely diagnosis and provision of information can help carers understand that behaviours are a symptom of brain disease and equip them with positive behavioural support strategies. Previous Australian research found that carer responses to aggressive behaviour tended to be reactive and crisis-driven.[34] Beneficial preventive strategies include environmental modification to address unmet needs of the person with dementia. Suitable care and support for the person may be protective in preventing the risk of offending situations.[35]

### 4.3. Supporting community participation

Our study, similar to a study in Sweden, revealed situations where people with dementia who were perceived as a public safety risk were banned from community venues, such as shops and social clubs.[36] We found that carers had mixed views on bans: they prioritise safety but deprive people with dementia of access to places that are practically and socially meaningful.[37] Carers sought ways to enable positive participation for their spouse or parent with dementia.

Access to support workers to accompany the person with dementia in activities can enable freedom to participate in the community and reduce carers' worries.[38] Carers can also be equipped with resources to educate community members and defuse problem situations. One strategy described here and in the Swedish study was the use of companion/dementia awareness cards to inform others of the person's diagnosis and avert 'uncomfortable or confrontational situations'.[39]

### 4.4. Law enforcement responses

Given the risk of harms to others, it is unavoidable that law enforcement personnel will sometimes be called to situations involving people with dementia, either at home or in community settings. Indeed, we found that in some circumstances the carer was the person who contacted police. A recent Australian analysis of police records indicated that 'family members of people with YOD who live at home sometimes require police assistance to manage physically capable people with behaviors that may escalate to violence'.[40] Consistent with the recommendation above, our study suggested more carer-focused education on recognising and responding safely to behavioural changes. Doing so could reduce the need for police involvement.

The way that incidents are characterised will likely influence police actions when called to respond. They may respond differently to an 'aggressor' or a 'shoplifter' than to a person with an illness. As Reutens and others observe, there is 'a lack of a cohesive conceptual framework for violence in dementia; that is, not all violence is offending but the perception often depends on whether the behavior is regarded as arising from the dementia or manifesting from characterological traits'.[41]

Relatively few studies have focused on policing practices where people with dementia are alleged perpetrators of crime, nonetheless, available studies have findings relevant to the issues of behaviours in the context of dementia. First, when called to respond to disturbances or situations of alleged offending that involve older people and those with a known dementia diagnosis, non-punitive resolutions can and do occur (eg police providing comfort and reassurance to the person, no arrests or charges).[42] This leads to the question of what features and actions support a therapeutic response and protect against criminalised responses. More research is needed. In our study, advocacy by carers when a person with dementia was detained was important, but there were still negative responses such as disbelieving that the behaviours were symptoms of dementia.

We add to the call for more police training on dementia, especially younger onset dementia.[43] The limited research in this area identifies a need for improved knowledge of dementia-related symptoms and behaviours, de-escalation strategies, training on interviewing people with dementia who are alleged offenders, and referral pathways.[44] It is also recommended that people aged 50 and older who are detained by police, especially for new-onset offending behaviour, should be referred and assessed for neurocognitive illness.[45] Doing so would support earlier diversion from inappropriate criminal legal responses.

Voluntary registries of people with dementia and other conditions are in place in some jurisdictions in the United States to improve police responses, primarily for missing person reports.[46] The value of such registries in

improving responses to behavioural situations, alongside dementia training for police, could be explored as an 'innovative public safety' infrastructure that supports carer efforts to be proactive in liaising with law enforcement.[47]

### 4.5. Strengths and limitations

This study provides new qualitative data on behaviours among people with dementia that could be perceived as possible criminal offending. It offers insights into how these behaviours manifest in home and community settings and responses to those situations, including contact with police or security personnel. Australian research that examined criminal court cases involving alleged offenders with dementia had a high proportion of males (90%).[48] Our focus on situations that precede charges and court proceedings included experiences of women and men, as carers and as people living with dementia. People served by the specialised university-based clinic where recruitment occurred tended to be from middle to higher socioeconomic backgrounds. Most participants lived in metropolitan areas, reflective of Australia's highly urbanised population.[49]

Our study elicited carers' experiences, and data from people with dementia was limited. Prior research indicates that people with FTD in particular 'usually have a diminished or absent sense for the behavioral, cognitive, or psychological changes that are reported by their relatives', meaning their own accounts are likely to be scant.[50] Accordingly, we anticipated that carers would be the main informants.[51] Research is needed on perceived offending among people with dementia who are First Nations or members of racialised communities also at risk of over-policing.[52]

In line with the qualitative descriptive method used for this exploratory study,[53] we sought to describe a phenomenon from the perspective of those experiencing it, rather than to build or apply theory to explain phenomena. Further theoretically-oriented work, especially on relational practices and dementia, will enrich knowledge in this area. For example, Jennings' work on solidarity and care argues for the mutually reinforcing nature of attention to and support for the needs of people in caregiving relationships.[54] More recently, Sherwood-Johnson and colleagues have proposed the concept of 'dangerous care' where dynamics of aggression, control and harm occur in the context of care for people living with dementia or other disabilities.[55] Existing theory has had a greater focus on older people with dementia and institutional care contexts,[56] and future theoretical development should attend to the circumstances of people with younger onset dementia and community participation.

## 5. Conclusion

Research has investigated the involvement of people with dementia in the criminal justice system, but there has been little attention to the early course of behavioural changes that lead to situations where behaviours may be perceived as criminal offending.[57] This study provides new insights, based on the accounts of carers of community-dwelling people with dementia, especially those with younger onset frontotemporal dementia. The findings of this work are timely in light of Australia's new *National Dementia Action Plan 2024–2034*, which emphasises that frontline services must be able to recognise and respond appropriately when they 'come into contact with people with dementia under heightened circumstances'.[58] Over the next decade, whole-of-community action is needed to advance progress towards a 'dementia inclusive society that understands people living with dementia … [and] actively enables them to fully participate in society'.[59] Improved awareness of dementia syndromes and behavioural symptoms is essential. Carers require timely post-diagnosis information and access to supports to enable care for the person with dementia as well as themselves. Dementia awareness should be strengthened for retail and hospitality venues

and associated security personnel, along with wider public education campaigns. Police and first responders require training that includes communication and de-escalation strategies. Information and training initiatives must be accompanied by investment in services to ensure timely diagnosis and access to supports that avoid stigmatising and criminalised responses to behaviours in the context of dementia.

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### Ethical standards

#### *Declaration of conflicts of interest*

Nola Ries has declared no conflicts of interest.
Fiona Kumfor has declared no conflicts of interest.

#### *Ethical approval*

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee (University of Technology Sydney Human Research Ethics Committee, Approval No. ETH22-7190) and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

#### *Informed consent*

Informed consent was obtained from all individual participants included in the study.

### Supplementary Material

Supplemental data for this article can be accessed online at https://doi.org/10.1080/13218719.2025.2568402.

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