

# Antipsychotic use for behaviours by persons with dementia in residential aged care: the relatives' perspectives

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## KEYWORDS

relatives, dementia, behaviours, antipsychotics, residential aged care

## ABSTRACT

### Objective

To explore relatives' experience, knowledge and perceptions of challenging behavioural and psychological symptoms of dementia (BPSD) and association with antipsychotic use for persons with dementia in residential aged care.

### Design

A qualitative Interpretive Description design using semi-structured interviews was used for understanding the construct and context of perceptions and experiences using a six-step process to analyse themes.

### Settings

South Australia, Victoria and Western Australia.

### Subjects

Six relatives of a person with dementia in residential aged care.

### Main Outcome Measure

Themes describing relatives' experiences, knowledge and perceptions of antipsychotic medication use for the person with dementia in residential aged care.

### Results

Three themes were identified: 1) lack of education and information - relatives found it difficult to differentiate between behaviours influenced by disease or antipsychotic medication; 2) need to be included in decision-making - relatives' believed challenging behaviours resulting from BPSD could be prevented with a more person-centred approach; and, 3) influence of aged care culture on attitudes towards use of antipsychotic medication - relatives' identified this could be problematic depending on use of agency staff and time pressures.

### Conclusion

Relatives of persons with dementia require support and education about the progression of dementia, BPSD and the risks and benefits that antipsychotic medication may have on BPSD. Most importantly, relatives need to be involved in decision-making regarding the use of antipsychotic medication. Nurses have a role to educate care staff on the use of person centred care in preference to medication for better care of the person with dementia.

## INTRODUCTION

Over 50% of residents living in residential aged care (RAC) have dementia (Australian Institute of Health and Welfare (AIHW) 2015). Caring for residents with dementia in RAC who display challenging behaviours resulting from Behavioural and Psychological Symptoms of Dementia (BPSD) is perceived by care staff as the most difficult aspect of managing the daily needs of these residents (Lawrence et al 2016; Ervin et al 2014). Behavioural and psychological symptoms of dementia can escalate in residents with dementia in the residential aged care setting due to neurobiological disease, staff or environmental factors, unmet needs, or chronic ill health, e.g. sensory loss, pain and urinary incontinence (Cohen-Mansfield et al 2015; Kales et al 2015). Brodaty et al (2003) found that up to 90% of residents in RAC will display BPSD based on these factors. To mitigate BPSD, antipsychotic medication may be used despite many recommendations for using non-pharmacological management first (American Psychiatric Association (APA) 2016; Kales et al 2015; Peisah and Skladzien 2014).

The use of non-pharmacological management is preferred as antipsychotic medication may elicit interactions with neuroreceptors that may adversely affect residents' health, e.g. postural hypotension and tardive dyskinesia (Kales et al 2015; Monthly Index of Medical Specialties (MIMS) 2015). For the person with dementia, antipsychotic medication may also increase morbidity and mortality (Park et al 2015; United States Department of Health and Human Services 2015; Kleijer et al 2009; Gill et al 2007) as well as mask non-dementia symptoms such as pain and delirium (APA 2016; Park et al 2015). Therefore, use of antipsychotic medication may not only be ineffective for addressing the cause of BPSD but, may act as a form of chemical restraint that can lead to physical and psychological harm (Peisah and Skladzien 2014).

To minimise the use of chemical restraint for the person with dementia, guidelines for non-pharmacological management have been generated by a number of professional organisations (APA 2016; National Institute for Health Care Excellence (NICE) 2015; World Health Organization (WHO) 2012). These guidelines emphasise the need to consider person-centred care as the initial non-pharmacological approach. Person-centred care considers the unique social context of a person's experience and how that experience may trigger behaviours associated with unmet needs, environmental factors or pain (Cohen-Mansfield 2001; Kitwood 1997).

It has been identified that limited training and education for staff in person-centred care compounded by low staffing levels impacts on the ability to use non-pharmacological management and contributes to antipsychotic medication use (Lawrence et al 2016; Cohen-Mansfield et al 2013; Ervin et al 2014; Productivity Commission 2011). Relatives of people who have dementia and live in a RAC setting have a key role to play in collaboration with care staff about behavioural management; yet, relatives' perspectives on the use of antipsychotic medication for the person with dementia in RAC remains largely unknown. The aim of this study, therefore, was to explore the relatives' perspectives on antipsychotic medication use to control BPSD for the person with dementia living in RAC.

## METHOD

Thorne's (2008) Interpretive Description qualitative methodology was used to explore relatives' understanding of the use of antipsychotic medication for managing BPSD in their relative with dementia in the RAC setting. The primary objective of this methodology is creating knowledge and understanding for practice that incorporates societal contexts influencing practice and the person in care (Thorne 2008). Use of this methodology enabled development of a comprehensive understanding of when antipsychotic medications were being used for the person with dementia as well as the context of engagement with relatives in relation to decision-making around their use. For this qualitative methodology, no specific number of participants is required. Rather,

data is collected until no new material or information arises from within the context being studied. Guest et al (2006) have indicated a total of six interviews are sufficient to determine themes in qualitative data analysis. For this research six respondents met the inclusion criteria. The four themes identified covered all qualitative data provided by the participants leading to saturation of information such that no new information emerged.

Ethical approval for the study was provided by Flinders University South Australia Social and Behavioural Research Ethics Committee (Project Number 6789).

Recruitment for the study was conducted through and with permission of Alzheimer's Australia (SA) via offline and online newsletters and networks. Relatives expressing an interest to participate were sent a letter of introduction and participant information sheet. Informed consent was given in writing or verbally at the time of interview. To be eligible for the study, relatives needed to be the primary carer or have experience of the person with BPSD and knowledge of the medications used to control those behaviours. The person with dementia needed to have resided in RAC within the past two years at time of interview in 2015.

Audiotaped semi-structured interviews were conducted face-to-face in a mutually agreed location or by telephone for between 30 minutes and two hours. Semi-structured interviews used open-ended questions about dementia, behaviours, antipsychotic medications and person-centred care. Participants were probed to elicit more detail about how knowledge was gained, how this knowledge may have influenced their perspective on antipsychotic medication use or behaviour management and other elements of importance relating to the societal context of antipsychotic medication use. Audio-taped interviews were transcribed and then analysed using Thorne's (2008) Interpretive Descriptive methodology as a framework to develop an understanding of the societal context of relatives' viewpoints on antipsychotic use and how this applied in nursing practice. Further analysis to identify barriers and facilitators for the use of antipsychotic medication instead of person-centred care was undertaken using the six-step process of Braun and Clarke (2006). This six-step process involved: familiarisation with the data; generating initial codes; searching for themes; reviewing themes; defining and naming themes; and producing a report (Braun and Clarke 2006, p87).

Trustworthiness of the data was established through addressing credibility, transferability, dependability and confirmability as defined by Oman et al (2003). Credibility of the data was confirmed by comparing and contrasting the occasions when antipsychotic medication use was described from one participant interview to the next as it developed within the context of RAC management of people with dementia with BPSD. This was then compared with what was known about this phenomenon as described by the literature. Transferability was confirmed through clarification of experiences described by participants with other nursing colleagues working in RAC, who were not part of the investigation. Dependability was assessed through review of the research design and process from colleagues in the residential aged care community and the transcription of data verbatim. Confirmability was ensured by all investigators evaluating the interpretation of the data and themes through the use of the 6-step process of Braun and Clarke (2006). By establishing trustworthiness through credibility, transferability, dependability and confirmability, commonalities arising from within the interviews could be compared with any alternative constructs emerging being tested against relatives' and nursing staff knowledge and experiences of the RAC. Furthermore, all authors cross-checked and reviewed the transcripts, participated in the analysis and agreed on the final themes and sub-themes generated.

## **FINDINGS**

### **Demographics of Participants**

From ten respondents, six relatives from three different Australian states met the inclusion criteria and participated in the study (table 1). All of the relatives were female with ages ranging from 45 to 62 years.

Frequency of visitation to the person with dementia's RAC facility ranged from daily to three or four times a week or once a fortnight. All relatives held healthcare advance directive authority.

Persons with dementia included four mothers, one husband, one father-in-law and one friend. Types of dementia identified included Mixed, Vascular, Lewy Body with Parkinson's disease and Alzheimer's disease. Persons with dementia ranged in age from 54 to 81 years and were in RAC ranging from one to three years at the time of interview. All relatives identified the use of Risperidone, an atypical antipsychotic, as one of the medications given to their relative in RAC. Participants are quoted throughout using pseudonyms to maintain confidentiality.

**Table 1 : Demographic information of participants (n=6) and persons with dementia (n=7)**

| Participants - Relatives |        |             |                 |                         | Person with Dementia |        |                  |               |
|--------------------------|--------|-------------|-----------------|-------------------------|----------------------|--------|------------------|---------------|
| Pseudonym                | Gender | Age (years) | Relationship    | Length of time as carer | Age (years)          | Gender | Type of Dementia | Length in RAC |
| P1                       | F      | 61          | Daughter        | 3 years                 | 80                   | F      | AD, LBD          | <1 year       |
| P2                       | F      | 56          | Daughter-in-law | 3 years                 | 71                   | M      | LBD              | 1.5 years     |
|                          |        |             | Friend          | 3 years                 | 54                   | M      | VaD              | 2 years       |
| P3                       | F      | 62          | Wife            | 2 years                 | 75                   | M      | FTLD, AD         | 1 year        |
| P4                       | F      | 45          | Daughter        | 8 years                 | 84                   | F      | AD               | 2 years       |
| P5                       | F      | 56          | Daughter        | 3 years                 | 78                   | F      | VaD, AD          | 3 years       |
| P6                       | F      | 50          | Daughter        | 2 years                 | 81                   | F      | AD               | 1 year        |

AD = Alzheimer's Disease, LBD = Lewy Body Dementia, VaD = Vascular Dementia, FTLD = Frontotemporal Lobe Dementia

### Themes

Three major themes were revealed relating to the societal context of antipsychotic use for the person with dementia in RAC. These themes are:

1. a lack of education and information;
2. the need to be included in decision-making; and
3. the influence of aged care culture on relatives' attitudes towards use of antipsychotic medication.

The description and analysis of these themes are elaborated further below.

### Lack of education and information

Relatives' perceived they were lacking knowledge about their relatives' dementia, medication management and behaviour in RAC. The lack of disease knowledge was articulated by Participant 1:

*I was never prepared for her getting up in the night and not knowing who I was..., for that lack of sleep and..., you know you put something down one day and give her something to eat that she would like... and the next day it would be "what's that"? I had no idea, I don't know how we managed (P1).*

The majority of relatives had little knowledge about antipsychotic medication, indicators for its use or the effects that it might have on behaviour. However, Participant 2 articulated that person-centred care was a better approach to prevent and manage challenging behaviours resulting from BPSD: 'I do know that antipsychotics were used to basically modify behaviour when in fact changing to a person-centred way of caring would have been far more appropriate' (P2). While Participant 3 understood that medication was preferentially used over person-centred care: 'Too often PRN (provide as necessary) is used instead of patient-centred management' (P3).

Although relatives' knowledge about dementia, behaviours associated with dementia and antipsychotic medication use differed, they were all able to articulate a sense of knowing what normal behaviour was for their relative, when that normality was upset and why. One participant provided an example from her father-in-law and friend: *'A few times they'd (father and friend) both say - why am I feeling drunk all the time? I'm not drinking any wine - they won't let me'(P2)*. While this relative understood that it was the antipsychotic medication making the relative feel differently, Participant 4 was less able to link behaviour to medication use:

*She was just really placid. Sometimes she would just be like a really frightened child...some of the bizarre behaviour, [I didn't know if] that was just because of the drugs or was that just part of the behaviour, and I wouldn't be able to know that (P4).*

The inability to differentiate behaviours resulting from medication use versus disease progression created discomfort and confusion in the relatives with regard to antipsychotic medication use for the person with dementia:

*It's also hard to know at each step, is it happening because of the disease or is she medicated? I don't know because she's become incontinent as well, so that's pretty tough on her too [be]cause a couple of times [when] I've been down for the weekend, she's soiled her pants and it really distresses her. I don't know if that's part of the lack of, is it being so relaxed that you haven't got control of your bowels or is it the disease? I don't know. (P6).*

After time, all of the relatives were able to distinguish medication effects from the regular behaviour of their relative after the person with dementia had been in RAC for a while:

*I used to call it her Campari (Risperidone). Some of the nurses would give it to her before I got there and she would be asleep when it was teatime. And to be asleep at teatime in a nursing home is awful because you're [not] going to [get fed]. Mum is a foodie as well so I know [she's] going to wake up later and [she's] going to be hungry and [she's] not going to get anything to eat until 8 o'clock the next morning, so that would make you pretty cranky (P1).*

Nevertheless, relatives were still puzzled and conflicted about when it was appropriate to use antipsychotic medication for their relative. This was because the use of antipsychotic medication traded-off one behaviour, e.g. calling out in a raised voice and disturbing other residents, for another, e.g. being quieter and less agitated. Although many relatives understood there may be a need for this trade-off, it was not necessarily a comfortable one for relatives to accept.

### **The need to be included in decision-making**

Lack of communication and education by care staff to relatives' about why antipsychotic medication was being used instead of non-pharmacological alternatives left relatives confused, anxious and frustrated as the personality and behaviour of their loved one changed. This did not engender trust in the process or staff as a participant described: *'Nobody volunteered information. In my memory, there wasn't a lot of volunteering, there was no counseling of her care. No, I don't think we ever got what we could expect' (P1)*. Participant 1's experience was common although not universal.

Two of the relatives were willing to have care staff take the initiative for antipsychotic medication use, but for four of the relatives, not being communicated with about care management, led them to seek out additional knowledge about dementia, behaviour management and antipsychotic medication use so they could be more actively involved in the decision-making that occurred as described in the following excerpt.

*Yes, I got a lot of information from their [Alzheimer's Australia] fact sheets and I got [some] from the care package through them so I used them a lot. Plus, I have a friend who is a lecturer's assistant so we both were skilled in dealing with problems from the wrong end and trying to sort back through it. So, Alzheimer's [fact sheet] was quite useful for that, and I would often refer a lot of people to 1800.... [Be]cause now that people knew Mum had it really bad and I'd have people saying can you talk to my Mum? And they'd come and talk to me or bring me to their house and I'd always say ring 1800 ... before you have a disaster, before someone gets hurt, before they wander away (P1).*

Not only did relatives gain knowledge from Alzheimer's Australia for when and how antipsychotic medication should be used for the person who has dementia, they also accessed television, support groups, Google, YouTube, the Internet and conferences to inform themselves. Participant 2 described information she received when attending a conference on dementia:

*Well, if you read the work that Brodaty (an eminent dementia researcher) has been doing with his study, he actually now says that dementia is the one contraindication to prescribing antipsychotics; that they should only be prescribed for people with true mental illness and dementia is not a mental illness (P2).*

As relatives' knowledge about dementia, medication management and behaviours increased, several relatives began initiating ways of caring for their relative to mitigate the effect of the antipsychotic medication. One participant described that she: *'Never 100 per cent succeeded on this, but if she (her mother) had her medicine just before dinner, she could eat some of what I took her and then she could settle down and the medication would take effect' (P1).*

Some relatives, such as Participant 2, became vigilant in making sure antipsychotic medication was not being used without their consent:

*They'd take him off (the medications) when we complained then the next pharmacy bill would come back in, and we'd find he'd been put back on. Then if we would forget to check or complain he would have just stayed on them (P2).*

Some relatives like Participants 2 and 4 described being frustrated and upset when informed of antipsychotic medication use after it had already taken place. Often this communication came via a bill for pharmaceuticals as described by one participant: *'I thought "oh, what's that" and I got the bill from the chemist and I Googled it but it was never sort of oh, we're giving your mother this' (P4).*

Not all relatives, however, felt the need to participate in medication management with care staff. Participant 6 preferred to be guided by the expertise of the staff:

*I'm guided by the professionals. They're very good at consulting, but they're also very good at getting their point across. They'll say, this is what we recommend and I'm sure if I said no it would be OK, but what if I said no and it wasn't the right decision? So, I sort of like to go with their opinion. I mean I feel it is a privilege that they are consulting with me really [be]cause they're the ones that are caring for her (P6).*

This illustrated the dilemma that all of the relatives faced – they had relinquished care of the person with dementia to professionals who they thought would know how to manage them better, yet the use of antipsychotic medication often left the relative and their loved one upset and uncomfortable. Managing the tension this caused relatives was dependent on the professionalism of the care staff and the culture of the residential aged care facility.

### **Influence of aged care culture on relatives' attitudes towards the use of antipsychotic medication**

Three of the relatives in this study had previous experience with the aged care system either personally or professionally (P1, P2 and P5) while for the others (P3, P4 and P6) their experience with RAC was new and associated with the entry of their relative to RAC. Participants with more experience, better understood different levels of care and felt more empowered to advocate for their relative as one relative described: *'I've had more ability to properly advocate for him in low care. The staff were more receptive. The staff were more willing to make changes or to be more person-centred'* (P2). This experience was not always able to overcome the administration of antipsychotic medication administration, however, and when relatives described inappropriate use of antipsychotic medication, they often referred to this as 'chemical restraint'.

Relatives describing antipsychotic medication use in this manner felt it was the RAC facility rather than the person with dementia who benefited as one participant described: *'They used to talk at the home quite often that they resisted any physical restraint or chemical restraint but you know, with the moods Mum used to have, sometimes she was chemically sedated or chemically restrained'* (P2). One relative felt the use of antipsychotics was: *'just a way of managing people... I suppose it does save them money so they don't have to have as many staff on if all the residents are just slumped in a chair or a bed'* (P4). Another participant was willing to concede that there might be times when it is beneficial to use antipsychotics: *'But I don't think it should be over-used like [staff thinking] 'we're too busy to deal with him, we'll just sedate him and put him to bed'* (P3). Nevertheless, one participant was able to describe the positive aspects of using antipsychotic medication as chemical restraint: *'She (Mum) was constantly on her feet walking everywhere, and I think that chemical restraint actually probably gave her a bit of a rest which I think was good for her'* (P5). Although some relatives accepted that antipsychotic medication may have had a place in the management of behaviour of their relative, it was more often the culture of the RAC that they emphasised as influencing its use.

According to all of the relatives, inadequate numbers of regular staff led to high rates of agency staff and the number of agency staff was a key indicator of antipsychotic medication use on their relative. If regular staff were present, one participant saw a marked difference in behaviour in her loved ones' when mainly agency staff were present rather than regular staff: *'In the early days, where Dad was, there was just this constant barrage of agency staff. Both Dad and my friend were just happier to see a person they knew. It's just that [they had that] level of being calmer because they knew people'* (P2). To alleviate the dependency of care staff on antipsychotic medication use, relatives offered ideas on alternative therapies and activities for their relative to mitigate BPSD behaviour. However, relatives often did not see these ideas acted upon as a participant explained: *'I gave them about 20 ideas for men, and I haven't seen any implemented. Sometimes I just feel the whole lot lack imagination'* (P3). Overall, not being able to sufficiently influence the care of their loved one, such that antipsychotic medication use could be avoided, left relatives feeling disempowered, ill-informed and dissatisfied with the care their relative received.

## **DISCUSSION**

In this study, most of the participants interviewed struggled to identify whether the behaviour displayed by their relatives with dementia in RAC was representative of disease progression or antipsychotic medication use. However, once relatives learned that the person with dementia was being treated with antipsychotic medication, relatives improved their knowledge, not only about the disease, but also about the applicability of this medication for the person with dementia. Relatives did this to distinguish for themselves the difference between deteriorating behaviour resulting from disease progression or some other factor such as antipsychotic medication use. Bonner et al (2015) indicated that much of the use of antipsychotic medication for the person with dementia was for non-psychotic purposes. Relatives in this study provided evidence of this by describing

occasions such as mealtimes when antipsychotic medication was used inappropriately and articulated their concerns about when and how this medication was being applied in relation to the direct need or behaviour of their relative at the time.

The results of a systematic review by Brownie et al (2014) recommended that to make the transition from home to RAC easier for families and the person with dementia, it was important to: facilitate partnership with family members in dementia care; provide access to information and promote communication with residents, families, counsellors and social workers; help residents and their families build coping skills; and continue meaningful activities for engagement and preservation of the social role of the resident. If these guidelines had been followed, trust between relatives and the care staff may have led to shared decision-making such that when BPSD arose, the method of management could be agreed upon without administering antipsychotic medication.

Lee et al (2015) identified that four key factors influence good practice in care of the person with dementia, namely; leadership and management of care, integrating clinical expertise, continuity of care and use of guidelines. Participants in our study identified these factors were missing as indicated by a lack of consultation with the relative, inconsistency in staffing, apparent lack of person-centred care and lack of information to relatives about when antipsychotic medication should be used.

Cornege-Blokland et al (2012, cited in Petriwskyj et al 2013) found less than half of family members consulted about antipsychotic medication use felt adequately informed about potential side-effects before consenting to its use. Relatives in our study who informed themselves about dementia, antipsychotic medication and its side-effects, felt empowered to advocate for better care of their relative. Nurses in RAC who accept and respect such advocacy may enable relatives to become more confident in the professionalism and clinical expertise of the care staff and facility. However, as Cornege-Blokland et al (2012, cited in Petriwskyj et al 2013) discovered, request for antipsychotic medication was most often initiated by nurses. This situation may undermine trust by relatives if antipsychotic medication is seen to be used for the benefit of staff rather than the person who has dementia with BPSD.

In our study, when relatives felt confident to trust that carers had sufficient clinical expertise to integrate the use of medication in the care management of their relative, then they were more accepting of its use at times designated by the nurse or carer for managing BPSD in their relative.

Livingston et al (2005) found that one of the few effective strategies for enhancing care of the person with dementia was education of staff on dementia, changes in staff behaviour, and different forms of BPSD management. When care staff are taught to use guidelines, such as those advocated by the National Prescribing Service (2013) on appropriate use of person-centred care and antipsychotic medication for the person with dementia, then it may be possible that the person with dementia in RAC will have a better chance of living the rest of their life without the burden of additional symptoms that inappropriate use of antipsychotic medication can bring (Park et al 2015). However, a study by Ostaszkiwicz et al (2015) found nurses in RAC indicated that although they knew person-centred care was a preferred method for managing BPSD in residents with dementia, they often felt using this method was better accomplished when the resident was sedated or had some form of restraint. Petriwskyj et al (2013) suggested there is still much to be learned in both research and practice of when and how to use antipsychotic medication and person-centred care for the person with dementia displaying BPSD.

Although participants in our study expressed they would have appreciated more shared decision-making about antipsychotic medication use as well as seeing the adoption of alternative methods of management of BPSD for the person with dementia in RAC, nevertheless, all relatives in this study expressed gratitude for

the efforts of most of the care staff they encountered and understood the pressures on care staff of trying to provide person-centred care within the RAC setting.

## CONCLUSION

This study identified three themes in relation to the societal context of practice affiliated with antipsychotic medication use for BPSD of people with dementia living in residential aged care (RAC) facilities. These themes were first, a recognition that relatives lacked sufficient knowledge to identify the source of undesirable behaviours occurring within the RAC setting; e.g. medication use or disease progression. To address this lack of knowledge, some relatives educated themselves about these issues to advocate for the person with dementia and prevent them from being subjected to use of antipsychotic medication rather than non-pharmacological care. Although knowledge and advocacy empowered relatives, this advocacy had limited success in decreasing the use of antipsychotic medication as the disease progressed as some relatives and care staff preferred the perceived benefits of the medication despite potential risks. The second theme identified barriers to provision of non-pharmacological management which relatives described as resulting from a lack of shared decision-making between staff and relative. Lack of shared decision-making led to the emergence of the third theme which centred on residential aged care practices influencing use of antipsychotic medication in RAC. Practices in favour of antipsychotic medication use were influenced by staff turnover, limited staff education and limited time to support non-pharmacological care management.

As a result of this study, it is recommended that nurses engage relatives in discussion about strategies for managing BPSD when this arises in the person with dementia in the RAC setting. To engage in such discussions, it is important for nursing staff and carers in RAC facilities to have knowledge about dementia, potential societal, physical, environmental and psychological causes of BPSD and to be prepared to offer non-pharmacological management of behaviour as first line treatment rather than depending on the expediency of antipsychotic medication administration. Discussions with family members should be conducted prior to the administration of the antipsychotic medication and in an informative and sensitive manner to avoid misunderstanding and negatively contributing to what is already an emotionally charged time for relatives and the person with dementia. This, in turn, engenders trust in relatives that staff are doing what is best for their loved one.

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