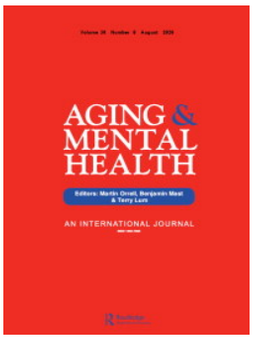

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Risperidone prescription and use for people with dementia in care homes: a qualitative study exploring perceptions of residents, relatives and health and social care professionals

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ABSTRACT

Objectives: Risperidone is an antipsychotic used to treat behavioural symptoms of dementia such as agitation, which should be used as a last resort. However, it carries a number of severe side effects, including stroke. Prescribing data suggest regular use outside of this guidance. We currently know very little about the first-hand experiences of people involved in prescribing decisions within care homes. This study aimed to understand perceptions around the risks and benefits of risperidone, preferences on how side effect risks are communicated, and how people feel about being able to better predict these risks.

Methods: Semi-structured interviews and one focus group were conducted with care home residents, relatives, and staff. A focus group was conducted with external healthcare professionals.

Results: Using framework analysis, five main themes were identified: (1) the interplay between the person and their symptoms; (2) balancing voices in decision-making; (3) what happens before prescription?; (4) bringing together information to make the right decision; (5) what happens after prescription?.

Conclusions: Care home staff and relatives of people with dementia were generally uncertain of the risks of risperidone, and the potential side effects were often not explained adequately. While risperidone continues to be prescribed, efforts to minimise harm are required. Specifically, improved education around the risks of risperidone is needed. Relatives wish to be involved in the decision-making process alongside care staff, and their involvement should be optimised through improved communication. Accessible dementia-specific guidance on monitoring risperidone after prescription should also be developed.

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social care; pharmacological management; risperidone; framework analysis

Dementia is a condition characterised by progressive memory loss, cognitive decline, and behavioural changes (Sachdev et al., 2014). Behavioural symptoms, including aggression and agitation, occur in around half of people living with dementia (Okura et al., 2010) and contribute to poor quality of life (Warren, 2022), potentially more so than cognitive impairment (Halpern et al., 2019). First-line treatments should include non-pharmacological interventions, however pharmacological therapy is sometimes indicated. Risperidone is the only atypical antipsychotic licensed for this indication in the UK. It is only modestly effective and comes with a significant side effect profile including increased risk of blood clots, heart failure, and stroke (Choma et al., 2025; Mok et al., 2024).

While prescription rates have decreased overall over the last decade, risperidone and other antipsychotics are still regularly prescribed broadly (Choma et al., 2025) and specifically within care home settings (Walsh et al., 2017). Understanding why pharmacological approaches persist despite guidance is critical to safer prescribing practices. Understanding the context in which prescribing risperidone occurs is key to bridging the gap between prescribing recommendations and practical use in care home environments.

Nurses and care staff regularly report having insufficient resources to implement non-pharmacological approaches (Jacobs et al., 2024; Kerns et al., 2018a) and view antipsychotics as safe, effective, and easy to implement (Kerns et al., 2018b; Ma et al., 2020; Raza et al., 2023). However, a better understanding of the culture of care homes, to the barriers and facilitators of appropriate prescription is needed to reduce prescription rates (Thompson Coon et al., 2014). This is

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particularly important as many people living in care homes are likely to be receiving prescriptions outside of the recommendations. Research conducted in Ireland sought to understand the context that requesting and prescribing antipsychotic medication occurs (Walsh et al., 2018). They concluded that care homes need clear guidance and support for better decisions around prescription to occur. Developing meaningful guidance around risperidone prescription in people with dementia in other countries requires similar qualitative work to gain an in-depth, multi-perspective understanding of the contexts prescribing occurs.

We aimed to qualitatively explore perceptions and attitudes of people with dementia, relatives, care staff, and clinicians towards the use of risperidone in care homes.

Method

Design

Semi-structured interviews and focus groups, analysed using framework analysis (Ritchie & Spencer, 2002).

Participants and sampling

Purposive sampling was used to recruit a sample with diverse experiences, *via* Clinical Research Networks and existing professional networks. People with dementia, their family members and care home staff were recruited, alongside healthcare professionals including nurses, old age psychiatrists, GPs and primary care managers. Participants from diverse backgrounds were recruited, with particular focus given to ethnic and cultural diversity.

The research team professional backgrounds include psychiatry, psychology, social care and general practice. All researchers who conducted interviews and analysis had backgrounds in psychology and social care.

Procedure

Semi-structured interview and focus group topic guides informed by existing literature were developed by the research team and PPI representatives, and refined during data collection. In-person (within care home) and online interviews and focus groups were conducted between April 2024 and October 2024. They were audio recorded and transcribed for analysis. Each participant received a £40 voucher for their participation.

Data analysis

Transcripts were analysed using framework analysis (Ritchie & Spencer, 2002), a form of thematic analysis, which explores patterns within qualitative data (Braun & Clarke, 2006). This method was chosen because it is both inductive (i.e. driven by prior knowledge and theory) and deductive (i.e. data-driven). Ritchie and Spencer (2002) five-step method was followed. Three researchers (DM, AWG and LS) independently familiarised themselves with the dataset and conducted line-by-line coding of two transcripts, meeting to develop the framework. Remaining transcripts were coded, with data systematically mapped to the framework, which was refined throughout data analysis, and quote placement consensus achieved through discussion.

Reflexivity

The influence of each researcher's positionality was explored, considering the understanding of risperidone prescription within a care home context that each individual held, and how this might interact with the data they collected and the subsequent data analysis. We acknowledged our extensive care home experience, in education, practice and research, which aligns with a person-centred approach to management of symptoms that may cause distress for the person with dementia and those around them. Several team members had also supported a relative who lived in a care home. We held pre-existing concerns around the potential risks associated with risperidone and how well these were understood within care homes. It was important to acknowledge this as a potential bias during data collection and analysis, incorporating perspectives that conflicted with the research team's positionality, such as where participants held positive attitudes towards risperidone but were unaware of potential side effects.

Ethical considerations

Ethical approval was obtained from London - Camberwell St Giles Research Ethics Committee Research Ethics Committee (23/HRA/4826). Participants provided written informed consent and could review their transcript upon request. Participants were made aware of the potential for distress when discussing issues around risperidone, and could pause/end the interview at any point. Care home residents living with dementia were recruited, with their capacity to consent confirmed by a trained researcher, in line with the Mental Capacity Act (2005). Researchers monitored for any signs of distress during interviews, and ensured that participants were offered regular breaks, and the opportunity to end their interview early if they experienced any distress.

Results

Four care homes were selected from South and West Yorkshire and South and West London, covering both rural and urban areas. Care homes were recruited to represent those above and below the

Table 1. Participant demographics.

	Residents with dementia ($n=2$)	Relatives ($n=4$)	Care home staff ($n=7$)	Healthcare professionals ($n=11$)
Age range	59–81 years	42–76 years	27–61 years	31–56 years*
Sex	Female $n=1$ Male $n=1$	Female $n=4$	Female $n=6$ Male $n=1$	Female $n=9$ Male $n=2$
Ethnic group	White British $n=2$	White British $n=3$ Black Caribbean $n=1$	White other European $n=3$ White British $n=2$ Multiple ethnic group $n=1$ Black British $n=1$	White British $n=9$ Indian $n=1$ Afghani $n=1$
Role (Care staff and HCPs)	N/A	N/A	Care Home Nurse $n=3$ Care Assistant $n=4$	Nurse $n=4$ Advanced Clinical Practitioner $n=2$ GP $n=1$ Consultant Old Age Psychiatrist $n=1$ Healthcare Assistant $n=1$ PCN Manager $n=1$ Quality Care Manager $n=1$

*Missing age data from three participants in the Healthcare Professional group.

Table 2. Overview of themes and Sub-themes.

Theme	Sub-themes
The interplay between the person and their symptoms	The role of communication in decisions Separating the person and their symptoms
Balancing voices in decision-making	Who knows the person best? Who holds the power?
What happens before prescription?	Why is risperidone prescribed? Antipsychotics as a last resort Medication being seen as a solution
Bringing together information to make the right decision	Balancing benefits and risks Knowing about side effects Accessibility of information
What happens after prescription?	How is risperidone monitored and reviewed? Avoiding sedation

average 30% rate of antipsychotic prescribing (McDermid et al., 2023). Within each region one nursing home (24 hour care provided with nurses always present) and one residential home (24 hour care provided without qualified nurses always present) were selected. Interviews ($n=16$) and one focus group ($n=8$) were conducted (see Table 1 for participant demographics).

Five themes were developed (see Table 2). These centred around a central tenet of drawing together the past, present and future for the person with dementia when making prescribing decisions.

The interplay between the person and their symptoms

Participants shared the importance of considering the person with dementia both as separate to and within the context of their symptoms, which fluctuate and change over time. Symptoms of agitation, in particular, guided decision-making related to risperidone.

The role of communication in decisions

Communication challenges contributed to experiences of agitation. Residents who are unable to communicate distress or pain are more likely to be prescribed risperidone.

> *"She would just cry and it's so heart-wrenching because she can say she's got a pain somewhere but sometimes she can't say what it is and that can be frustrating for her."* – Relative 2

Relatives felt that they communicate on behalf of residents and over time become their *'talker'*. They spoke about the cognitive shift in family roles, and the need to now make decisions on behalf of their loved one, acknowledging that their relative's *'power is gone'*.

The loss of self that their relatives experienced was felt to be integral to decision-making. Participants emphasised the importance of remembering the person behind the symptoms.

> *"It is difficult because sometimes if you're honest with yourself and you know the person… you ask yourself the question… Would this person be happy to see themselves like this?"* – Relative 1

Separating the person and their symptoms

Symptoms of agitation were felt to lead to personality changes. This influenced prescribing decisions, as medication was seen to help the person 'regain' their personality.

> *"Well since he has been having these episodes, it has gotten a bit nasty… Yeah short tempered, he is very impatient which he never ever was… and it's not my husband. It seems as though it is somebody else."* – Relative 4

Relatives had significant emotional responses to the personality changes, which were integrated into prescribing decisions.

> *"When she came out of hospital it was ridiculous, she was sky high, shouting, screaming, kicking. Never seen my mum like that, to the extent where I left here one day and crashed my car. That's how it affected me."* – Relative 2

Balancing voices in decision-making

Communication between care homes, clinicians, and families around decisions to prescribe risperidone varied, as did involvement in decision-making. People with dementia were not consistently involved in these decisions.

Who knows the person best?

The importance of involving family members in decisions to prescribe risperidone was widely recognised. The knowledge care staff had of residents offered a view that provided context around recent experiences.

> *"You don't want to see her how she is, so anything [that staff suggest] could help her would help me because I'm getting distressed as well as she's getting distressed."* – Relative 2

Importance was placed on the views of care home staff, as they spent the most time with the residents. They were at times seen as the people who know the residents best, which was challenging to communicate with relatives.

> *"Care home staff are with clients day in, day out so they notice the behavioural changes and they know what impact that's having on them… Obviously we are going in once a week for ward round or having a conversation on the phone and just seeing a snippet of that."* – Clinician 2

However, other care staff felt excluded from such decisions, feeling they were *'always at the end of the communication'*. Staff they received insufficient information about newly admitted residents, which meant they were unprepared to deliver care.

> *"We don't have access to the [medical records]. We might receive some information from the hospitals, but we very often are unaware of that person being on risperidone. Very often we don't receive that information… we're treating the patient blindly."* – Care home nurse 3

Permanent staff were considered better placed to share information in prescribing decisions than agency staff, who might *'miss things because they just don't know'*, as not all staff have equal levels of knowledge. The importance of knowing residents well and having the '*whole picture*' of their presentation available was emphasised.

Who holds the power?

In some settings, relatives felt that they held a powerful role in decision-making, which continued after prescription.

> *"Having a discussion that allows balance and reasonable negotiation that really does place my dad at the centre of that decision-making, not just a means to managing someone's behaviour."* – Relative 1

Family members advocated for their relatives and recognised behaviour changes, but deferred prescribing decisions to professionals. There was a sense of helplessness when their relative's behaviour caused upset or distress.

> *"I said to [care assistant] this can't go on, something needs to happen… then they spoke to the GP… and then he said to me I think we're going to change the medication to this [risperidone] and then I said just try anything if it need be."* – Relative 2

Where there was a more distant relationship between the relative and care home, relatives were informed of medicine changes prior to them taking effect, but were not directly involved. In some cases, relatives were informed of changes as a courtesy.

> *"Relatives are just informed that they are on that medication… and if there is too much sedation then they voice their concerns. Families aren't consulted prior, they are more informed about it."* – Care home nurse 3

This led to some relatives feeling powerless during the decision-making process.

> *"They said they wanted to put him on it and I didn't have a choice really."* – Relative 4

Furthermore, the relationship with clinicians was important. Clinicians often led decision-making and perceived that care home staff generally deferred to them around medicines management. This meant that staff views could be disregarded, or not even sought, with their agreement assumed. Care staff felt they were integral in the decision-making process, as they know the residents better.

> *"They don't tend to battle back [decision to prescribe risperidone]… as long as the person is not punching someone… they are eager to go with what the professionals are saying".* – Clinician 2

Multiple stakeholders complemented the decision-making process, but could also create issues and delays. Where communication was poor, care staff lacked knowledge about risperidone and the associated review process.

> *"I don't understand when someone's on risperidone, how is it being reviewed? That is always my concern. When will they see whether if they wean them off it, they go back to being aggressive?"* – Care assistant 1

Ongoing communication was prioritised, however this often benefitted and reassured family members rather than residents. Participants noted that the term antipsychotic can *'make people nervous'*.

"The main issue is not getting the medication prescribed [or] involving the health professionals in making this particular decision. It's giving reassurance and educating the relatives about antipsychotic medication." – Care home nurse 1

Information shared by external healthcare professionals was not always sufficient for relatives to make informed decisions. Flexible support such as phone calls and emails were appreciated.

"The information was not enough for the daughter to understand…. So I called a meeting with the GP and the consultant… They had a long meeting and after (she) felt… very reassured, she was very happy to try [risperidone]." – Care home nurse 1

Visual aids were used to support discussions around prescribing risperidone, but could be used to persuade relatives that side-effects were less concerning than they believed.

"I've used [visual aids showing stroke risk associated with risperidone] quite a lot actually and it's quite helpful… the visuals with other side effects are really helpful because then we can tell them yes it can happen but it doesn't always happen and at the moment the risks are so high that we have to prescribe it." – Clinician 1

Developing and maintaining relationships over time with relatives allowed clinicians to manage the emotional reactions of relatives, allowing them to personalise their communication style. One clinician felt relatives may be less willing for their loved one to be given risperidone due to the potential personal guilt if severe side effects were experienced. They perceived that if a resident had a stroke following prescription, the relative may feel that they had *'allowed it to happen because they have allowed that prescription'.*

"I spend a lot of time building relationships, because you can be honest and say 'look now we are in difficulty… potentially your loved one is going to need medication, but it's not scary. It's good for them. It's a positive thing'. If you can build that into something that doesn't feel overwhelming, you tend to find that families are very supportive." – Clinician 11

Further inequities were highlighted, with some doctors, particularly GPs, reluctant to initiate risperidone. Participants felt they needed to *'make a nuisance of myself'* to get prescriptions reviewed, and another felt they had to *'push onto doctors to actually prescribe [risperidone]'*. There were perceptions that GPs prefer not to prescribe risperidone, which was felt to be frustrating, when they were not managing the complex behaviours of care home residents daily.

What happens before prescription?

Risperidone was primarily prescribed due to difficulties in managing agitation, aggression, and risks associated with non-pharmacological approaches alone.

Why is risperidone prescribed?

Risperidone was prescribed when *'every other avenue'* of non-pharmacological approaches were unsuccessful. Stigmatising language towards behaviours associated with agitation was seen.

"Sometimes we try to not prescribe the medication and see if we can do things to make them behave differently and make them less challenging and aggressive. With some, it works very well. Some of them, unfortunately, need the next step, which is risperidone." – Care home nurse 1

Behavioural symptoms of dementia were reflected on, including residents being '*unsettled, anxious, agitated and restless*'. Reducing risk to the resident and other residents was a priority. Participants considered the perspective of someone with dementia, to understand why they may experience agitation. However, at times, care staff felt unable to identify alternative strategies to support residents.

"I'd say his physical, violent outbursts, where he grabs me on my shoulders and holds very tightly… I'm not really strong enough to get him off… I'm not really sure how to deal with that without asking for help." – Care assistant 2

Risperidone could also ease care staff and relative distress, which was felt to impact on the quality of care delivered.

"[Risperidone] relieves the pressure of the carers… We need them to be okay, it's the fundamental thing and if they are a little bit more hopeful and a bit more positive, they are not so frightened anymore." – Clinician 2

Antipsychotics as a last resort

Knowledge of residents, and continuity of care helped external healthcare professionals deliver appropriate and supportive care. Residents benefitted from interactions with familiar clinicians. However, sometimes participants spoke about the impact risperidone can have on the care home environment, and how one resident can impact on others.

"If the person is a risk to others that [risperidone being successful in managing agitation] brings the unit back to normal because it's like a domino effect: if one person starts, all the other residents will follow, and that's kind of the dangerous thing." – Care home nurse 3

Non-pharmacological or pharmacological approaches with a less severe side effect profile were prioritised before risperidone. Participants reflected on the multiple strategies that had been tried ahead of prescription, with risperidone being a last resort.

"When I have used it [risperidone], it is kind of the last step… you try all the other non-pharmacological or safer

pharmacological options first, and it's only if the risk, to the patient or to staff is high to justify its use." – Clinician 5

Clinicians considered a person's medical history and best practice guidance when prescribing. Cardiovascular risk factors were considered, although tests were inconsistently offered to residents. In some cases, this led to initiations conflicting with national guidance.

"We always carry out an ECG, a full health review… prior to commencing any antipsychotics, unless they have no significant heart risk or previous stroke risk then we would start at a very low dose." – Clinician 2

Medication as a solution

Participants reflected on what they considered to be positive impacts that risperidone had in managing symptoms, often related to calmness or reduced activity, reducing symptoms such as '*doing the same thing, by walking, aggression, being very active, or just shouting in their bedroom, banging*.' Risperidone could also allow for the deprescribing of other medications due to its effectiveness in managing various symptoms.

"Introducing risperidone has reduced the rest of her medication. She doesn't need Lorazepam anymore. She was on a lot of painkillers because she was agitated, she was banging her legs and arm everywhere and now she doesn't need that. She's just on a tiny dose of risperidone, and she's doing fantastic." – Care home nurse 1

However, questions were raised over whether risperidone offered a solution to such behaviours, or a quick fix to mask complex situations. This required effective leadership to ensure appropriate procedures were followed.

"I think there is sometimes an anxiety of 'this resident has difficult behaviour' and wanting a solution to that quickly because it is very disruptive to [care home staff] and other residents. Sometimes it's 'can we start risperidone?', really keen to get something done." – Clinician 5

Bringing together information to make the right decision

Prescribing decisions involved weighing up complex information, balancing the perceived benefits with the potential for serious side effects.

Balancing benefits and risks

Severity of symptoms and associated risk were central to decision-making. This was measured by disruption to the person and the environment around them.

""The risk of stroke and other side effects, I think in the short term that those risks are not as much as the benefits of stopping them from harming themselves and harming others and so… if we don't prescribe, we are increasing the risk of other things." – Clinician 1

Some relatives were willing, despite associated risks, to try risperidone in the hope of improved quality of life. This often reflected poor understanding of potential side effects. Others had reluctance to initiate risperidone due to possible side effects. Clinicians then supported families to weigh these risks against benefits.

"[Family's] concern… is also the risk of heart attack and stroke, especially if they haven't had any cardiovascular risks or events, they are like 'no, why would I start this because actually they are gonna have a stroke?'… where of course we would come in and be like 'this is no quality of life, you know they are very confused.'" – Clinician 2

Holistically assessing an individual's risk profile was also an important consideration. Clinicians reported a nervousness in prescribing if there is a history of cardiovascular events, where they would consider anti-dementia medications as an alternative.

"You know, somebody who's very frail, overly sedated, falls, risks, lots of other polypharmacy where it's going to cause lots of problems. Risperidone is probably not going to be the solution because of all those other risks." – Clinician 5

One resident felt that they would not consider the side effects in the decision to receive risperidone if they were experiencing agitation, and would want to prioritise reducing this, but would be guided by clinicians and care home staff.

"[I'd accept it] if I got aggressive, yeah" – Resident 2.

Knowing about side effects

Knowledge of the side effect profile of risperidone varied greatly, with care home staff looking for support from external healthcare professionals to identify and monitor less obvious side effects.

"[Care staff] are people with big hearts who want to love people and look after them and give them the best they can. I rely heavily on my relationships with the GP and pharmacist, because they are your experts." – *Clinician 11*

Relatives wished to be *'better informed'* about side effects. Some felt reluctant for their loved one to be given risperidone once learning of the cardiovascular risks because they *'wouldn't want to risk it'*. However, other relatives acknowledged that everyone reacts to

medication differently, and a sense of desperation led to prescription.

> *"Everyone's different. You can go on numbers but that's not necessarily gonna be my mum. Because if ten of us take it and nine of us [have a stroke] and one don't, you know that's nine or it could be the other way around."* – Relative 2

Knowledge of the risks of risperidone has improved over time, however this had not necessarily been cascaded to care home staff. Care home staff focused on supporting relatives to be aware of the risks, but perceived that these were not frequently seen, which reduced the weight given to these in conversations. Sedation was particularly pertinent when monitoring side effects, as this led to immediate action.

> *"We've learnt to understand and approach people with dementia differently. Twenty years ago… it used to be 'give them the risperidone if they start getting upset or getting agitated', whereas now we look at different ways of approaching somebody and being able to de-escalate, rather than medicating them."* – Clinician 4

Accessibility of information

More accessible information about risperidone is needed, as *'education is key'* in helping people better understand and monitor risks. Care home staff reflected that relative views may be formed by poor understanding.

> *"We really struggled because she was presenting very bad behaviour and… [in a conversation] with the daughter, I explained that probably the next step was going to prescribe risperidone to help her with the behaviour… but she kept refusing. Then I understood that the information was not enough for her to understand the medication."* – Care home nurse 1

Insufficient information led to *'panic around antipsychotics'*, and understanding the rationale for prescription concerned relatives.

> *"I would like to know how it affects the brain. I would like to see what dementia is doing to the brain and then show me what the medication does to alter that."* – Relative 4

Sources of accessible information

The patient information leaflet was frequently the primary source of information and learning. Some relatives not only learned about the benefits and side effects, but learned that the medication was an antipsychotic from reading this. However, this required individuals to take initiative to read this. Receiving verbal information from care staff helped others to translate medical terms and provided an opportunity to *'ask questions then and there'*. For others, prescribing decisions were made without all parties fully informed.

> *"[Staff member] sat me down and said 'this is what the doctor prescribed, let's give it a go' and I agreed. I didn't know what the disadvantages were."* – Relative 2

Opinions differed on how the risk of side effects should be presented. When asked if they would want to know the numeric risk, a resident responded *'Me being me, I would say yes'*, while their relative shared *'I would say no'*. Another resident shared that they would *'like to know everything'*, but would prefer to know stroke risk as a percentage. A relative wanted to see a table showing the pros and cons of risperidone, or a *'traffic light system'*, as *'for some people, the jargon is mind boggling'*.

What happens after prescription?

Differences existed in monitoring for side effects, avoiding sedation, and defining the success of risperidone.

How is risperidone monitored and reviewed?

Timelines for reviewing risperidone prescriptions varied. However, flexibility was key. Review timelines depended on the individual and care home. Immediate changes in behaviour were expected to justify ongoing prescription, with some GPs reflecting they '*would like to know if it's working within a week initially*', whilst others expected the GP to keep this in mind when they visited.

> *"We do an antipsychotic medication review every three months. Obviously the doctor is always [in the care home], so the medication is actually reviewed more than that, but especially for the antipsychotic medication…even if the person doesn't present with any change, we still review the dosage, the medication and the reason why the person has to continue or stop that particular medication."* – Care home nurse 1

Inconsistency in reviews was particularly challenging, as timelines often contradicted existing guidance, which is not tailored to older adults living with dementia and therefore was not always felt to be appropriate.

> *"We'd flag up that it would need a review at the 6 or 12 week mark, and then depending on the response to that and the safety, it would be whether or not they need 3 month, 6 month, annual reviews. I don't think there's a one size fits all to how much patients would get reviewed."* – Clinician 5

Several outcomes were considered during reviews, including cardiovascular examinations and falls risk. Clinicians were reluctant to deprescribe risperidone. Involving relatives within reviews helped to foster a meaningful relationship between the relative and

care home, and ensured relatives felt *'confident and comfortable'.*

"Close monitoring is the main thing. If I went to someone who I have just prescribed it and then they are complaining about headaches, nausea, vision changes, loss of balance, then I suppose we would have to review it you know and most likely bring them off it unfortunately and try something different." – Clinician 2

Avoiding sedation

Participants were keen to avoid unwanted sedation. Residents not being *'so aggressive anymore',* were balanced with avoiding them being *'zombified'*.

"I would say, honest to God, that risperidone is a killer of a person. It basically makes people not be themselves, being lethargic, withdrawn, kind of not present. Even with the little dose you know, half of the risperidone sometimes. Most people are more withdrawn… they are sedated." – Care home nurse 3

Signs of sedation caused panic amongst relatives, and led to urgent reviews and at times, deprescribing.

"Well the drowsiness, not connecting with me… change it straight away, don't even think about it. Change it." – Relative 2

Care home nurses felt they had a unique perspective, bringing together medical and social care expertise with understanding any changes in residents' daily routines.

'If the nurse is seeing that the person is not interacting, not eating or drinking… then it's very likely the medication will be stopped… It's not just the family view, it's the nurses as well'. – Care home nurse 3

Discussion

This qualitative study identified five themes capturing important insights in the contexts surrounding risperidone use in dementia. *The interplay between the person and their symptoms* focused on placing the person living with dementia at the centre of decision-making. Participants highlighted the need to remember that there is a person behind the symptoms, which should be focused upon through delivery of person-centred care, and questions were raised over who held the most relevant information to inform prescribing decisions. This is broadly consistent with best practice, however there is a highly complex context in which prescribing occurs, with a particular focus on the impacts of agitation on both a person's personality, and the wider environment within which they sit (i.e. other residents and staff). As dementia progresses, family members find their relatives become more reliant on them. However, care staff have a crucial role in delivering person-centred care and informing prescribing decisions (Raza et al., 2023).

Balancing voices in decision-making was integral to making a decision that met the needs of the person with dementia. We identified an imbalance between clinicians, care home staff, and relatives of people living with dementia in the knowledge of risperidone and it's risks and benefits. In line with existing evidence, we found that relatives can be insufficiently involved in decisions to prescribe risperidone and are instead informed about its use after initiation (De Bellis et al., 2017). Communicating the risks and benefits was most successful when both a clinician and care home staff member invested time to explain the risks and benefits associated with risperidone to a resident and their family. Care home staff also experienced exclusion from prescribing decisions and felt uninformed.

Reflecting on *what happens before prescription*, involved establishing an understanding of the resident's feelings and behaviours. Behavioural and environmental approaches were preferable to prescription, but risperidone was frequently prescribed. Reductions in distress were intertwined with prescribing decisions for relatives, whereas some care staff felt risperidone contributed to a more manageable environment. With risperidone remaining at times a necessary last resort, it is imperative that guidance is accessible and consistent (Beeber et al., 2022) to promote safer prescription.

Bringing together information to make the right decision involved carefully considering the potential risks and benefits. While care staff reported being aware of the increased risk of falls and sedation, some were unaware of the associated cardiovascular and stroke risks. This is particularly important as care staff play a key role in communication between clinicians, residents and relatives (Toles et al., 2018). Care staff are eager to receive training on risperidone and efforts should be made to improve education. Training care staff on the appropriate use of antipsychotic medication could influence their beliefs about risperidone and reduce prescription (Raza et al., 2023). Some care staff and clinicians felt the most important aspect of prescribing was reassuring relatives, however residents themselves were rarely mentioned.

People with dementia spoke about their preferences for hypothetical prescribing situations in the future, sometimes expressing opinions that contrasted with their relatives. Advance care planning could ensure that the wishes of people living with dementia for their future care are captured and documented appropriately (Wendrich-van Dael et al., 2020). Whilst symptoms of agitation that require a risperidone prescription may not be experienced by many people with dementia, incorporating their

preferences for hypothetical situations could help reduce the emotional burden for relatives in decision-making.

Participants worried about stroke risk, particularly for residents with a relevant medical history. Clinicians screened for cardiovascular and stroke risk factors with an ECG and evaluated a person's medical history prior to commencing risperidone. While this concern is positive, risperidone appears to increase the risk of stroke for people with dementia regardless of comorbidities or medical history (Choma et al., 2025). This could influence decisions to prescribe the medication as it indicates no one group is necessarily safer to initiate prescription with. This could reduce feelings of guilt for those involved in decision-making. Discussions around *what happens after prescription* highlighted variability in monitoring risperidone prescriptions in terms of review frequency, onset after prescription, and outcomes assessed. Individuals are being prescribed risperidone for longer than the recommended six weeks (NICE, 2018a), and ongoing monitoring practices differ. Avoiding sedation was a priority for care staff and relatives after initiation, and there is a fine line between reducing agitation and causing sedation. Nurses in care homes play an important role in identifying and monitoring for such side effects. Implications for practice

The present study identified that residents are prescribed risperidone for longer than recommended (NICE, 2018a). Existing guidance should be updated to consider the complexity of prescription and monitoring for people living with dementia, which may lead to lower prescription rates (Kalisch Ellett et al., 2019). This is particularly important due to the variability in monitoring procedures. Participants acknowledged a delicate balance between potential risks and side effects, and perceived therapeutic benefit when making prescribing decisions, identifying shared decision-making as best practice (Daly et al., 2018). Communication is key for antipsychotic prescriptions for people with dementia (De Bellis et al., 2017). Our research suggests various methods to improve communication. Relatives reported a preference for both verbal and visual information when learning about the risks and benefits associated with risperidone. An infographic using different colours to display associated stroke risk per 100 people was suggested, which can be seen in the NICE (2018b) decision-aid for antipsychotic prescribing. A 'traffic light system' outlining the severe risks (red) of risperidone, other potential side effects (amber), and the benefits (green), and a table comparing the risks and benefits of various medications, were also suggested. Visual aids can be an effective tool in communicating health risk probabilities (Garcia-Retamero & Cokely, 2013), but should support, rather than replace, conversations with healthcare professionals. Experiences of residents and relatives were best when they established a strong and trusting relationship with care staff, who are key to the meaningful and effective sharing of information. It is therefore crucial that visual decision-aids are accessible and understandable for care staff.

Current monitoring guidance is based on younger people with schizophrenia (NHS England, Yorkshire and the Humber Clinical Network & London Clinical Network, 2023) and may not be appropriate within this context. There is a need to develop dementia-specific evidence-based guidance for monitoring, to ensure appropriate practices are applied consistently. Until this is produced, reviews will be completed based on guidance potentially inappropriate for people with dementia, and variation in procedures is likely to continue. The NICE decision-aid (NICE, 2018b) should also be updated to reflect the latest data on stroke risk associated with risperidone (Choma et al., 2025). This should detail the risk of stroke for those with relevant comorbidities and should outline that the relative risk of stroke is equal for everyone with dementia who is prescribed risperidone.

Limitations

We aimed to recruit care home residents who had been given risperidone, but this proved difficult. Those who were prescribed risperidone within care homes where we recruited participants from were less able to communicate clearly to participate in an interview. The two residents who participated did not have experience of risperidone, but we were able to ascertain their views on hypothetical experiences. Whilst we achieved a wide range of participants in terms of age and ethnicity in some participant groups, we lacked male representation and our sample was predominantly White British. While we gathered views on risperidone from participants from a range of backgrounds, our data could have benefitted from recruitment of a more diverse sample.

Conclusion

This study underlines the need for appropriate and accessible guidance on both the prescription and ongoing monitoring of risperidone in people with dementia in UK care homes. Limited awareness of the severe risk profile associated with risperidone exists among care home staff and relatives. Transparent communication is important in achieving appropriate prescription, monitoring, and discontinuation of risperidone. Improved education around the risks and benefits of risperidone is needed. While non-pharmacological approaches are preferable, risperidone will continue to be prescribed, meaning that efforts to minimise harm are essential. An accessible decision-aid should be developed, alongside

dementia-specific guidance for monitoring people on risperidone in care homes.

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