Antipsychotic Medication in Dementia; The good, the bad and the ugly!

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Different types of antipsychotic medication

Antipsychotic medication was developed to be prescribed to people of working age experiencing a psychotic condition like schizophrenia. These drugs weren’t developed to be prescribed to older people or people whose brains are damaged by dementia. Older types of antipsychotics are called ‘typical’ antipsychotics or major tranquillisers. They include thioridazine, promazine and stelazine; they are not licensed for the use of people with dementia and are rarely prescribed now. Haloperidol is a typical antipsychotic and is still used frequently.
Newer Types of Antipsychotic Medication

• Other types of antipsychotics are called ‘atypical’ antipsychotics. These include risperidone and olanzapine and, since being available from the mid-1990s, increasingly were prescribed for people with dementia. In the late 2000s, this began to change with the publication in 2009 of a major report from the Department of Health into antipsychotics for people with dementia, which questioned their heavy use.

• Risperidone is now the only drug licensed for very cautious use with people with dementia, and then only in situations involving ongoing aggression for up to six weeks, with the person being very closely monitored for ill-effects.
Antipsychotic Drugs

• Antipsychotic drugs are also the drugs most commonly prescribed for behavioural and psychological symptoms, such as aggression or hallucinations, in people with dementia. In some people antipsychotics can eliminate or reduce the intensity of certain symptoms. However, they also have serious side effects.
Sube Banerjee – drawing lines in the sand

• “There have been increasing concerns over the past years about the use of these drugs in dementia. The findings of my review confirm that there are indeed significant issues in terms of quality of care and patient safety. These drugs appear to be used too often in dementia and, at their likely level of use, potential benefits are most probably outweighed by their risks overall. This is a problem across the world, not one just restricted to the NHS. It is positive that, with action, we have the means with which to sort out this problem, quickly and safely” (Sube Banerjee 2009)
Hazards!

‘It has become clear that people with dementia as a whole are at higher risk of potentially serious adverse effects from antipsychotic medication’.

Professor Sube Banerjee, in The use of antipsychotic medication for people with dementia: Time for action (Department of Health, 2009)
Caution

‘Approximately one-third of people with dementia live in a care home and it is this group who are most likely to be prescribed antipsychotics’.

Dementia Alliance 2016
Unpleasant side effects

- Problems with the use of antipsychotics for people with dementia include their unpleasant and disabling side effects. And Older people are more likely to experience these side effects.
- Antipsychotic medication can make the person feel very drowsy or cause their arms, legs and head to move without them meaning to, or make their body go very stiff or tremble. Not surprisingly, these effects can make it very hard for a person who already has difficulties as a result of their dementia to maintain their current abilities, for example, going to the toilet or dressing themselves. Taking antipsychotic medication may make it difficult for someone to speak clearly or understand what is being said to them, to eat and drink or even sit or stand up comfortably.
- People who know or care for the person may not realise that the drug is causing these changes and may think that the person’s dementia has worsened. Sometimes, there is relief that the person’s behaviour has become less challenging, although their needs remain unmet and their wellbeing is seriously compromised.
Dangerous side effects

• Antipsychotic drugs can make people, especially older people, ill. They can cause dehydration and water retention, they can increase the likelihood of chest infections or they can cause heart problems. These effects make people more vulnerable to other illnesses, for example if people become dehydrated, they are more likely to develop urine infections. There is an increase stroke risk.

• Studies estimate that there are at least 1,800 extra deaths each year among people with dementia as a result of them taking antipsychotics, and that the likelihood of premature death increases if people take these drugs for months or years rather than weeks (Department of Health, 2009).

• People who have dementia with Lewy bodies or Parkinson’s disease generally do not benefit from antipsychotics. They may cause all the effects mentioned above with no benefit.
The benefits of stopping antipsychotics

• Although a small minority of people with dementia taking antipsychotics won’t benefit from stopping the medication or a reduced dosage, the majority will. People generally get relief from the side effects of trembling, loss of motor control, tiredness and water retention, among others, and feel better in themselves. People’s abilities often improve and they find that they are able to function much better on a daily basis. It may even seem that the dementia has improved. Sometimes carers and family are amazed by the change in a person’s appearance, energy levels and capacity to engage when they have stopped taking antipsychotics or reduced the dosage.
What are psychotic symptoms?

• People who live with severe mental health problems, such as schizophrenia, experience what are called ‘psychotic symptoms’. People with dementia can experience psychotic symptoms too. Hallucinations are an example of a psychotic symptom: they involve seeing, hearing, tasting, smelling or feeling something that isn’t actually there. The most common type of hallucination is hearing voices, or what is called an ‘auditory hallucination’.

• Another type of psychotic symptom is a ‘delusion’, which means that a person holds very unusual beliefs about themselves or those around them. A person may believe that they are God or another religious figure for example. More frighteningly, they may believe that someone or something is trying to harm them. This is known as a ‘paranoid delusion’.
Psychotic symptoms and dementia

• Some people with dementia experience psychotic symptoms, although hallucinations are more likely to be something the person sees rather than hears. It may be thought that someone is experiencing delusions when actually they have misinterpreted what is going around them, for example the person believes that someone has stolen their money because they don’t remember where they put it.

• Hallucinations and delusions are more common in some types of dementia than others. People who have dementia with Lewy bodies (DLB), for example, are quite likely to experience the same visual hallucinations over and over again because of the way this type of dementia affects the brain.
BPSD

• The research literature often refers to behavioural and psychological symptoms of dementia (BPSD), which are a group of symptoms common in people with Alzheimer’s disease and related dementias, and especially common in care homes. Between 70-90% of PWD will experience a BPSD at some time or other.

• Antipsychotic medication began to be used to treat a wider range of what are sometimes called ‘behavioural and psychological symptoms in dementia’. These include aggression, agitation, restlessness, depressed mood, anxiety
Neuro Psychiatric Inventory (NPI)

- Delusions
- Hallucinations
- Depression
- Anxiety

Frequency X Severity;
Maximum score in each domain =12

A score of 12 in any domain means PWD is extremely distressed

- Agitation / Aggression
- Elation
- Apathy
- Disinhibition
- Irritability / Labilty
- Aberrant Motor Behaviour
- Night time behaviour
- Appetite
Understanding the Person

• If a person with dementia develops any of these changes, it is important to remember that they are not to blame or ‘behaving badly’. Their symptoms may be a direct result of changes in their brain, or because of a general health problem such as discomfort caused by pain or infection.

• These symptoms can also be related to the care a person is receiving, their environment or how they are spending their time. For example, the person may be agitated because they are anxious or because they are somewhere that is very noisy. Symptoms can become worse because the person’s dementia makes it harder for them to make sense of the world.
People with dementia who develop non-cognitive symptoms that cause them significant distress or who develop behaviour that challenges should be offered an assessment at an early opportunity to establish the likely factors that may generate, aggravate or improve such behaviour. The assessment should be comprehensive and include:

- the person’s physical health
- depression
- possible undetected pain or discomfort
- side effects of medication
- individual biography, including religious beliefs and spiritual and cultural identity
- psychosocial factors
- physical environmental factors

Behavioural and functional analysis should be conducted by professionals with specific skills, in conjunction with carers and care workers. Individually tailored care plans that help carers and staff address the behaviour that challenges should be developed, recorded in the notes and reviewed regularly.
Assessment

‘A proper assessment and a thorough understanding of the role of the array of interventions available for people with dementia is essential so the correct and safest treatment can be delivered’.

Professor Alistair Burns in Optimising treatment and care for people with behavioural and psychological symptoms of dementia (Alzheimer’s Society, 2011)
Efficacy of treating pain to reduce behavioural disturbances in residents of nursing homes with dementia: cluster randomised clinical trial

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Abstract
Objective To determine whether a systematic approach to the management of pain can reduce agitation in people with moderate to severe dementia living in nursing homes.

Design Cluster randomised controlled trial.

Setting 60 clusters (single independent nursing home units) in 16 nursing homes within five municipalities of western Norway.

Participants 363 residents with moderate to severe dementia and clinically significant behavioural disturbances randomised to a stepwise protocol for the treatment of pain for eight weeks with additional follow-up for four weeks after the end of treatment (33 clusters; n=176) or to usual treatment (control, 27 clusters; n=177).

Intervention Participants in the intervention group received individual treatment for agitation and distress for eight weeks according to a stepwise protocol, with paroxetine (pantopramol), morphine, bupropion, quetiapine, or pregabalin. The control group received usual treatment and care.

Main outcome measures Primary outcome measure was agitation (scores on Cohen-Mansfield agitation inventory). Secondary outcome measures were aggression (scores on neuropsychiatric inventory-nursing home version), pain (scores on mobilization-observation-behavior-intensity-dementia-2), activities of daily living, and cognition (mini-mental state examination).

Results Agitation was significantly reduced in the intervention group compared with control group after eight weeks (ANCOVA analysis of covariance adjusting for baseline score. P<0.001): the average reduction in scores for agitation was 17% (treatment effect estimate -7.0, 95% confidence interval -11.7 to -2.3). Treatment of pain was also significantly better for the overall severity of neuropsychiatric symptoms (p=0.03) and pain (p=0.01), but the groups did not differ significantly for activities of daily living or cognition.

Conclusion A systematic approach to the management of pain significantly reduced agitation in residents of nursing homes with moderate to severe dementia. Effective management of pain can play an important part in the treatment of agitation and could reduce the number of unnecessary prescriptions for psychotropic drugs in this population.

Trial registration ClinicalTrials.gov NCT01021669 and Norwegian Medicines Agency EudraCT 2008-007465-25.

Introduction
Thirty five million people worldwide have dementia, and this number is expected to increase to 115 million by 2050.

Agitation and aggression are common in people with dementia, in particular those with moderate to severe dementia living in nursing homes, where the cross sectional prevalence of these symptoms exceeds 50%. Agitation is associated with increased distress to residents and a burden to nurses, relatives, and professionals. It is one of the most challenging symptoms for clinical management. Antipsychotics are often used as first line drug treatment for agitation and aggression, which are 40-60% of residents with dementia in nursing homes prescribed such treatment.

In the United Kingdom alone, a report for the Department of Health estimated that 180 000 people with dementia were being prescribed antipsychotics, causing 1620 excess strokes and 1800 deaths a year.

These figures emphasise the importance of finding safe and effective ways to reduce agitation and aggression in people with dementia.

Many people with dementia have painful conditions, and it has been proposed that pain in patients with impaired language and abstract thinking may manifest as agitation. Thus more effective treatment of undiagnosed pain may contribute to the overall prevention and management of agitation. Overall, 51.80% of

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No Quick Fix!

• The doctor should discuss with the person and/or their carer what symptom or symptoms they are prescribing a drug for, and they should then monitor how it is working. Don’t expect immediate results in people taking drugs for behavioural and psychological symptoms. Any benefits may take several weeks to appear. Drugs may also stop working. This is because dementia is a degenerative condition, meaning that the chemistry and structure of the brain will change during the course of the illness.
Starting Antipsychotic Treatment

- All drugs have side-effects which are usually related to dose, so the doctor will often begin by prescribing a small dose and then gradually increase this until the best balance of benefits and side effects is achieved. This approach is sometimes known as ‘start low and go slow’
- ECG is usually required before treatment and repeated part way through
- Side Effect Monitoring – pre and post
Starting Treatment

• The risks and benefits of taking an antipsychotic should always be discussed with the person with dementia, where possible, and any carer. The first prescription of an antipsychotic should only be done by a specialist doctor. This may be an old-age psychiatrist, geriatrician or GP with a special interest in dementia. The doctor should explain the alternatives, the symptoms that are being targeted, and plans to review, reduce and stop the antipsychotic.

• When the prescription is reviewed, the doctor may suggest stopping the drug in one go (for people taking a low dose of antipsychotic) or a more gradual reduction (for people on a higher dose). In either case, the effect on the person’s symptoms should be closely monitored.
Who can antipsychotics help?

- Drug trials have shown that risperidone has a small but significant beneficial effect on aggression and, to a lesser extent, psychosis for people with Alzheimer’s disease. These effects are seen when the drug is taken for a period of 6–12 weeks. Antipsychotic drugs may be prescribed for people with Alzheimer’s disease, vascular dementia or mixed dementia (when it is usually a combination of these two). If a person with Lewy body dementia (dementia with Lewy bodies or Parkinson’s disease dementia) is prescribed an antipsychotic drug, it should be done with the utmost care, under constant supervision and with regular review. This is because people with Lewy body dementia, who often have visual hallucinations, are at particular risk of severe adverse (negative) reactions to antipsychotics.
Who can antipsychotics help?

• Antipsychotic drugs do not help with other behavioural and psychological symptoms such as distress and anxiety during personal care, restlessness or agitation. These symptoms need other, more individualised, approaches. For people with mild-to-moderate behavioural and psychological symptoms of any kind, the National Institute for Health and Care Excellence (NICE) recommends that antipsychotic drugs should not be prescribed in the first instance. The non-drug approaches outlined above should be used for these symptoms.
Risperidone

- Risperidone is licensed for the short-term treatment of aggression in Alzheimer’s disease, if aggression poses a risk or the person has not responded to non-drug approaches. It is only licenced for PED who have a diagnosis of alzheimers disease.
Other Antipsychotics

• Other antipsychotic drugs prescribed for people with dementia are done so ‘off-label’. This means that the doctor can prescribe them if they have good reason to do so, and provided they follow rules set out by the General Medical Council. The latest recommendations are that an antipsychotic other than risperidone should only be prescribed for a person with dementia if they have psychosis (delusions or hallucinations) that developed before – and so is not caused by – their dementia.
Testimonies

• “I hold them responsible for his rapid loss of speech, the constant drooling, his mask-like frozen expression, the constant jerking of his right foot that stayed with him for the rest of his life, and rapid onset of incontinence. While still able to walk, he would walk leaning over sideways or backwards at an alarming angle, and no doubt it was this ‘unbalancing’ that caused the hip fractures. Soon he developed epileptic fits and I cannot be sure that it was not related to the antipsychotics.” - Carer of a person with dementia living in a care home

• ‘A small study at Sheffield Health and Social Care NHS Foundation Trust has shown that certain people with dementia show substantial reductions in symptom severity and substantial improvements in quality of life when they are prescribed antipsychotics. The results also show minimal adverse effects when intensive systematic monitoring is in place. The results cite the personal beneficial impact for people with dementia and their families’

Rusius / Bainbridge
Testimonies

• “My mother was prescribed these while I was living at home with her. They were given because she was anxious...from that day onwards her speech diminished and she suffered with the shakes. I haven’t been happy with the drugs for some time. The dose was reduced at my request and Mum started to talk a little more, but then I went on holiday and while I was away the dose was upped again to higher than the original. I do not feel these drugs have benefited my mother in any way and I have seen plenty of negatives.” - Carer of a person with dementia living at home

• “While there is a lot of evidence showing the negative effects of taking these drugs, little is written about the sometimes positive effects when a person is very frightened and agitated. It may mean that the person can remain with their carer for a lot longer when taking a small amount of antipsychotic medication.”

   Admiral Nurse
Good Practice Questions

- Why is the person being prescribed an antipsychotic? Which symptoms is the drug meant to be helping with?
- Have possible medical causes of these symptoms (such as infection, pain or constipation) been ruled out?
- Can non-drug approaches be tried first?
- Do we need to know more about the person as an individual to work out what may be causing their symptoms?
- How will we know if the drug is working?
- What side effects might the drug cause?
- What is the plan for the person to come off the antipsychotic?
- When will the use of this drug be reviewed?
Questions ?