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Next issue: September 2014

EDITORIAL

Welcome to the June 2014 issue of RAC Communiqué, in which we examine two cases involving the use of medication for residents who have dementia and the associated behavioural and psychological symptoms (BPSD). This topic continues to be hotly debated in clinical settings and popular media. Caring for persons with dementia requires a considered holistic approach, empathy, tolerance, and managing risk to self and others. Being able to do this in the middle of the night with competing demands from other residents is not an easy task.

The findings from research studies are generally consistent and clear about the limited efficacy of medications in treating BPSD. However, alternative practical real life solutions are often difficult to consistently apply. This issue of RAC Communiqué is somewhat longer than usual, as we wanted to include the details of each case and an expert commentary.

We would like to thank the hundreds of subscribers who complete the survey evaluating the RAC Communiqué. The responses are being collated and we will publish the results later this year. Finally, we are giving the RAC Communiqué and our website a 'makeover' to coincide with the return of our sister publication, which is focuses on acute hospital care.

LIST OF RESOURCES

1. Understanding the brain and behaviour: An extremely informative DVD which explains the functions of the brain and how changes in brain pathology impact on a person's behaviour. Available from Alzheimer's Australia Victoria http://www.fightdementia.org.au/victoria.aspx

2. The Dementia Behaviour Management Advisory Service is a national service funded by the Commonwealth Department of Social Services to provide 24 hour practical advice and assistance to those caring for people exhibiting BPSD. http://dbmas.org.au/

3. The Dementia Training Study Centres aim to improve the quality of care and support provided to people living with dementia and their families through the provision of dementia education and development opportunities for health professionals. http://www.dtsc.com.au

4. A Handbook for NSW Health Clinicians - Dementia. This articulates a framework for NSW health staff in the assessment and management of people with BPSD. A publication by the NSW Ministry of Health and the Royal Australian and New Zealand College of Psychiatrists May 2013. https://www.ranzcp.org/Files/Publications/A-Handbook-for-NSW-Health-Clinicians-BPSD_June13_W.aspx

5. THE USE OF RESTRAINTS AND PSYCHOTROPIC MEDICATIONS IN PEOPLE WITH DEMENTIA. An Alzheimer's Australia publication that is designed to provide the evidence of current practice, consequences, legal issues and alternative approaches. http://www.fightdementia.org.au/common/files/NAT/20140321_Publication_38_A4_print%20version_Web.pdf

CASE #1 THE DRUGS DON'T WORK!

Case Précis Author: Joseph E Ibrahim, Monash University

Clinical Summary

Mr AAA was a 63 year-old male who was a resident at a RACS-1 for just two weeks. His medical history included frontal dementia for one year, diagnosed at a Memory Clinic of a large metropolitan hospital. The diagnosis had been reviewed to fronto-temporal dementia and familial motor neurone disease about six months before his death.

Mr AAA was an inpatient at a large metropolitan hospital for a number of weeks to manage behavioural issues due to the dementia. Mr AAA had absconded on a number of occasions, would raise his fist when prevented from doing things he wished to do and had displayed sexually disinhibited behaviours.

Cyproterone, an anti-androgen was commenced and seemed to be effective in suppressing the sexual disinhibition. Sertraline and risperidone were also prescribed to manage the behaviours and he was stable at discharge to the RACS-1.

At the RACS-1 Mr AAA tried to leave on several occasions, was often found near the door, was sexually disinhibited and had made threats to hit other residents. Mr AAA's family were appointed as his guardians and sought to move him to RACS-2 which was closer to their home.

On 5 September 2006 Mr AAA was admitted to a secure dementia ward of RACS-2. Overnight, he was restless and displayed sexual behaviour towards an agency carer. The carer responded by walking away and Mr AAA returned to his room. Later, in the early morning Mr AAA spoke to staff using phrases that were threatening and sexual in nature. The staff member was experienced and unperturbed, simply documenting the event.

The following night, Mr AAA had remained awake, agitated and wanting to leave the RACS. A RN assessed him in the morning. Mr AAA's demeanor became aggressive, swearing, raising his fist and threatening harm. The RN firmly explained that he should desist and there was some improvement.

A second RN was involved mid-morning when Mr AAA managed to get out of the secure unit by somehow accessing the code to the secure doors. The DoN and another staff member were able to talk him into walking back to the unit.

The general practitioner was contacted and prescribed 10mg of haloperidol to be given intramuscularly (IM), haloperidol 5mg orally on an as needed or 'PRN' basis, but not more frequently than 4-hourly and an increase in the dose of risperidone. Mr AAA cooperated in the administration of the intramuscular injection by willingly lowering his trousers and underpants.

Over the next 24 hours Mr AAA was administered 5mg haloperidol at 8:30pm (Day-1) and at 1:50pm, 6pm and 11:50pm (Day-2). The next three days no PRN haloperidol was given then he had three doses on the Day-5 at 6am, 10am and 8:30pm. The following morning (Day-6), Mr AAA's daughter contacted the General Practitioner to review the level of sedation and medication use. The GP ceased the PRN haloperidol and lowered the dose of risperidone.

Two days later (Day-8), around mid-morning, Mr AAA was found in his room, awake but not responding to questions and looking 'unwell'. The nursing staff asked for the General Practitioner to be contacted to review and possibly transfer to an acute hospital. Over the next two days Mr AAA remained pale, was eating very little and had multiple falls. When staff noted shallow breathing and a weak pulse, the ambulance service, GP and family were called (Day-10). The paramedics arrived and were not able to revive Mr AAA.

Pathology

The cause of death following an autopsy by a forensic pathologist was a cerebral infarction (stroke). The toxicology testing of bloods taken at autopsy reported the presence of haloperidol.

Investigation

An Inquest was held in August 2010, and required seven sitting days and another day in August 2011. The administration of the intramuscular, and then the oral, haloperidol was the focus of much attention at the Inquest.

Circumstances surrounding Mr AAA's admission were not entirely clear. The admission documentation for RACS-2 could not be found. The Director of Nursing at RACS-2 gave evidence that she rang RACS-1 and was told they were not experiencing problems with behaviour.

The Coroner noted that reasons for the nursing staff administering the PRN doses of haloperidol were not always documented and when documented were not clear. Often described as 'restless' or 'to settle'.

There was some suggestion that a member of staff may have contacted the GP's rooms to be told that he was not available until the afternoon. However, no message was left for the GP and there was no follow-up by RACS-2 staff to make contact.

An expert overview of the case was obtained from a consultant in geriatric medicine who noted that Mr AAA had compromised breathing as a result of his motor neurone disease affecting the muscles of the chest wall leading to hypoventilation and sedation. The expert was concerned about the amount of haloperidol administered and said that there was a considerable inconsistency in the reasons for administration of haloperidol. He expressed the view that the haloperidol played a role in the death along with the possibility of a peri-stroke delirium and the respiratory muscle compromise from the motor neurone disease.

Coroner's Findings

The Coroner was reluctant to make a formal finding as to a cause of death that differed from cerebral infarction, as without the stroke, death would not have occurred.

Recommendations

The Coroner commended a publication that was a comprehensive review of management of dementia in general practice with a focus on cognition and behaviour. The coroner recommended that this should be drawn to the attention of medical practitioners in general practice who regularly manage dementia patients, particularly in nursing home settings and that the Minister for Health take such steps as are necessary to draw this review to the attention of such practitioners.

Editor's note

We have not cited this publication as it was published in 2008 and there are more contemporary guidelines available.

CASE #2 IF ONLY SOMEONE WOULD SIT WITH MUM

Case Précis Author: Joseph E Ibrahim, Monash University

Clinical Summary

Ms BBB was an 83-year-old woman whose medical history included severe hearing and visual impairment, cognitive impairment, hypertension, atrial fibrillation, chronic obstructive pulmonary disease, esophageal reflux, frequent urinary tract infections and osteoarthritis of her knees. Following a fall and dislocated shoulder complicated by hallucinations and episodes of anxiety in June 2009, Ms BBB was admitted to RACS-1 for respite care. Ms BBB often called out, was restless, repetitive and disruptive in the evening when her family left. Staff administered Lorazepam as required.

Another fall caused a fractured pelvis and multiple rib fractures requiring management in an acute hospital. For the management of behaviour, quetiapine and PRN haloperidol were added to the medication regimen. Ms BBB was transferred to another site for rehabilitation with an aim to return home. Unfortunately, Ms BBB failed to improve sufficiently and was transferred again to await long-term care placement. On admission to RACS-2 diagnoses included osteoporosis, hyponatremia, coronary artery disease and dementia. Notes indicated that Ms BBB had "anxiety attacks", could be disoriented, but responded to gentle touch and hand holding. On initial admission in November, Ms BBB was pleasant and cooperative at times, but could be 'disruptive, demanding and calling out'. The dosing and frequency of administration of medication increased with little benefit, when calculated over one month (December) she received 28 doses of Lorazepam 1mg, four doses of haloperidol IM and nine doses of haloperidol 5mg orally. Haloperidol was administered primarily for yelling or aggressive behaviour. In January, the RACS-2 sought an urgent consultation from the Psychiatric Assessment Services, who attended and discussed interventions with the staff. They asked that a Dementia Observation Scale be administered for one week to look for behaviour patterns or triggers, a reassessment for pain and to explore available services through the Institute for the Blind. The social worker's notes indicated that reassurance and tending to Ms BBB's needs calmed her for a few minutes and that haloperidol was ineffective. Recreation therapy notes indicated that she was attending some programs, could be disruptive, but with one-on-one attention, would settle with hand holding and rubbing of her back. By the middle of January, Ms BBB was eating poorly, refusing medications, not as noisy as usual and had developed a reddened area on her right buttock. The family requested that the haloperidol be discontinued and the psychiatrist suggested Ms BBB be assessed for extra-pyramidal side effects as she was on very high doses of typical neuroleptics. The medication regimen was reviewed, the antipsychotic changed, Lorazepam reduced and the psychiatrist advised Ms BBB would need very gentle care due to her significant sensory deficits. By late January Ms BBB was yelling out asking for water, yet refusing it after only one sip. Staff administered haloperidol 2.5mg with "very little effect" and Ms BBB received five doses of haloperidol 2.5 mg over three days. Over the next few days, the family was becoming increasingly concerned about her drowsiness. Ms BBB had increasing leg oedema, was refusing diuretics, had developed a stage 3 ulcer with blackened edges over the coccyx, and a wound on the right heel. Staff was now using a mechanical lift to get her out of bed and an air mattress was requested.

On January 31, Ms BBB was transferred to an acute care hospital. A 'Do Not Resuscitate' order was put in place and over the next several days in hospital she remained very confused, with high pitched screaming. A range of medications including lorazepam, morphine, acetaminophen, tramadol hydrochloride, morphine intravenous and fentanyl were trialed to no effect. After discussion with the family comfort care was provide and Ms BBB died several days later.

Pathology

Following an autopsy and toxicology testing the cause of death was: 1. Acute bronchial pneumonia

2. Combined effects of morphine, fentanyl and tramadol may have contributed to the death.

Coroner's Findings

Ms BBB's family requested a review of the medical and nursing management provided and whether the administration of medications may have contributed to death.

An extensive review including an expert committee determined in general, the pharmacological treatments for Ms BBB were considered appropriate with the exception of the dosage of haloperidol administered. The expert committee was unable to determine the degree to which sedating medications contributed to death and noted her response to medications was, at best, inconsistent.

Recommendations

1. Staff and including medical practitioners in RACS should be provided with education on pharmacologic and non-pharmacologic management of Behavioural and Psychological Symptoms in Dementia (BPSD).

2. Funding should be made available to RACS to assist with the non-pharmacologic management of challenging behaviors, particularly after a resident's admission to a new environment.

3. All RACS should have immediate access to outreach teams to assist with the management of BPSD or specialized behavior units to accept residents transferred for more in-depth assessment and treatment.

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FEEDBACK

The editorial team is keen to receive feedback about this communication especially in relation to changes in clinical practice. Please email your comments, questions and suggestions to: racc@vifm.org

DISCLAIMER

All cases that are discussed in the Residential Aged Care Communiqué are public documents. A document becomes public once the coronial investigation process has been completed and the case is closed. We have made every attempt to ensure that individuals and organisations are de-identified. The views and conclusions are those of the authors and do not necessarily represent those of the Coroners, Department of Health, Victorian Institute of Forensic Medicine or Monash University.

EXPERT COMMENTARY

Dr Margaret Winbolt, PhD; GradDipAdvNurs(Gerontic Nursing); RN. Senior Research Fellow, Director Victoria and Tasmania Dementia Training Study Centre, Australian Centre for Evidence Based Aged Care, La Trobe University.

This commentary draws on information from the 2011 Annual Report of the Geriatric and Long-Term Care, Review Committee Office of the Chief Coroner, Province of Ontario November 2012.

General Comments

There is no doubt that caring for persons with dementia who exhibit BPSD causes difficulty and distress to staff in all care settings. In both cases it was said that staff seemed to turn very quickly to the use of medicines to manage BPSD and that limited non-pharmaceutical interventions were tried prior to administering medicines. In both cases, medication continued to be administered despite there being little clinical response. It makes no sense to continue medication when there is no improvement in behaviour. The decision to continue to administer medicines should be informed by comprehensive and clear documentation of the reasons for, and the effect of each PRN dose. Another complicating factor is the multiple transfers to different locations in both cases highlighting the need for open, clear and comprehensive communication.

The use of medications in the management of BPSD should always be viewed as the last resort and, if used, should be done so only after having given careful consideration to the associated risks and potential side effects. These medicines may contribute to increased sedation, (as seen in both cases), leading to a reduced oral intake and dehydration, sometimes worsening a delirium (Mr AAA) and increased muscle stiffness (i.e., extra-pyramidal symptoms) causing immobility which may contribute to pressure injury (Ms BBB).

Underlying causes for the behaviours, such as untreated pain, urinary retention or adjustment difficulties, should be addressed and non-pharmacological interventions trialed first. A team approach is required, often involving some or all of the following: the family, nursing staff, general practitioner, pharmacist, geriatrician, aged mental health psychiatrist, psychologist and neuropsychologist.

Pharmacological management of BPSD

There is little evidence of the effectiveness of medications in managing BPSD and certain types of behaviour do not respond well to pharmacological intervention, though there are a small number of medications that may have some benefit in managing aggression, agitation and depression in persons with dementia. Benzodiazepines and antipsychotic agents have not been shown to be highly effective in the management of BPSD. These medications may cause confusion, falls, and sometimes even increase agitation.

Delirium often occurs in persons with dementia leading to deteriorations or changes in behaviour. The use of benzodiazepines and haloperidol are usually of little, if any benefit.

We should be cautious and conservative with the prescribing and administration of antipsychotic agents following the principle of 'start low and go slow'.

Non-pharmacological management of BPSD

In contrast to the limited evidence for the effectiveness of pharmacological interventions for BPSD there is ample evidence to support the use of non-pharmacological strategies when these are tailored to the behaviour and needs of the individual.

So, what are you supposed to do in the middle of the night on a weekend?

1. Review the resident's medical status: urinalysis; bowel assessment; fever; pain

2. Explore any recent events which may impact on behaviour: staff changes, room changes, other residents, visitors etc. as in the case of Mrs BBB where, due to her significant sensory deficits, any change in environment or staff was likely to exacerbate her symptoms of BPSD

3. Try a variety of interventions, and focus on being specific for each individual resident

4. Call the Dementia Behaviour Management Advisory Service (DBMAS): 1800 699 799 (24 hour helpline).