Translating what we know about pain recognition and management in people living with dementia

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The aim for today

• To take you on a “whistle stop” tour of a module developed for a specific part of the aged care workforce on “Working with pain in people living with dementia

• To use that as a foundation for further discussion around this issue
My brief for this project

• Informed and engaged by DCRC
• Data from a Questionnaire and Individual Manager Interview Needs Analysis (DBMAS workforce) identified a need for an in-service module around Pain in People living with Dementia
• This module needed to be;
  – Evidence Based
  – Be brief - 30 – 40 min presentation
  – Specific to the target group : PCA’s and R’N; s working in the residential aged care setting
• Developed in consultation with the end users
Full package

- Lesson Plan
- PowerPoint slides (contains more than required)
- Handouts for participants
- Facilitator notes – discussion points (attached to each slide)
- And a comprehensive evaluation component
Aims

• To update pain and pain management practice for dementia residents with current pain management research while reviewing relevant good practice

• To improve the quality of life for people living with dementia in residential care who have pain
Objectives

At the end of this session participants will be able to:

• **Identify** pain in people living with dementia
• **Describe** the options in pain assessment tools for people who are living with dementia
• **Understand** the principles of pain management for people living with dementia
• **Know** how to access additional resources in this area.
What is pain
People with dementia are at greater risk of having their pain:

• Unrecognised
• Under assessed
• Inadequately managed

Why do you think this is so?
What can we change to make a difference?
Possible Discussion Points

• Among older adults with dementia who are in long-term care, the prevalence of pain or potentially painful conditions is high, with estimates ranging from 43% to 71%.
• People with dementia can not describe their pain.
• What you do not see you do not acknowledge or treat
• Increased understanding of the impact of pain in people living with dementia will lead to appropriate assessment and management and increased quality of life.
May be described by residents as:

- Tingling
- Throbbing
- Dull
- Tightness
- Piercing
- Electric
- Or may deny that they have any signs at all
- Tenderness
- Aching
- Shooting
- Itching
- Tearing
- Sharp
- Pounding
Cancer Pain

Individuals with cancer experience both acute and persistent pain syndromes, which are associated with their tumour or with another painful condition unrelated to it. Most acute pain problems that cancer patients encounter are caused by common diagnostic or therapeutic interventions. Moreover, many cancer patients with well-controlled persistent pain have transitory ‘breakthrough’ pain.
Ways in which health professionals may describe pain

Pain may be

— Acute
  • less than a month

— Chronic
  • persists for more than month

— Acute on chronic
  • acute exacerbation on top of a chronic pain issue
Or by the source of pain i.e.

Nociceptive pain

• located in visceral (body's internal organs) and somatic receptors (skin)
• may arise from tissue inflammation, mechanical deformation and ongoing injury or disease
• examples include arthritis, fractures, musculoskeletal problems, skin ulcers and intra-abdominal conditions.

Neuropathic Pain

• results from damage to the peripheral and/or central nervous system.
• Examples include diabetic neuropathy, sciatica, phantom limb pain and trigeminal neuralgia
Pain may be associated with Psychological/Psychiatric Issues...but remember!!!!

“The term 'psychogenic' assumes that medical diagnosis is so perfect that all organic causes of pain can be detected; regrettably, we are far from such infallibility... All too often, the diagnosis of neurosis as the cause of pain hides our ignorance of many aspects of pain medicine.”  Ronald Melzack, 1996
Pain is:

“Whatever the experiencing person says it is, existing whenever he(she) says it does.” (Margo McCaffrey 1968)
## Causes of pain in the elderly

**Common include**
- Osteoarthritis
- Cancer
- Neuropathies
- Bowel diseases
- Joint immobility's
- Fractures

**AND MANY MORE**

**Less so – or less noticed include**
- Podiatry related
- Poor dentition
- Pain in genital/anal area due to thrush, constipation, haemorrhoids
- Bony protrusions due to weight loss
- Decubitus Ulcers
Living with Dementia and Pain
But what if you have dementia?

My father was screaming in the nursing home. The staff had tried changing any number of his medications, but nothing stopped his agitation until the physician ordered Vicodin, a strong painkiller. I called the physician and asked him to assess what might be causing my father’s pain. The physician suggested it might be arthritis.

In a calm voice, I suggested that perhaps the pain was from something more serious—would he please do an evaluation? He told me that this would be hard to do since my father has dementia and can’t tell him what hurts. I pointed out to the physician that, although limited in his speech, my father does respond to "yes" and "no" questions and that the doctor might be able to tell what hurt by looking at my father’s facial expression.

http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1043
But what are some barriers to staff perceiving pain in people living with dementia

- Lack of recognition of pain
- Lack of sufficient education and/or training
- Misdiagnosis or a late diagnosis
- Non-use of assessment tools
- Changing staff
Things that will negate those barriers

• Knowing your residents living with dementia (understanding their individual cues)
• Being intuitive and perceptive
• Participating in education and training
• Using appropriate tools
• Undertaking regular pain assessment on all residents
• Utilise history from families
What might be some non verbal cues to pain?

- Any behavioural change
- Mood changes
- Impact on Speech and vocalizations
- Facial Expressions
- Agitation and aggressiveness
- Changing body language
Assessing Pain
Assessment

If pain is not recognised it cannot be treated.

Assessment of pain is the prerequisite for successful pain management.

Difficulties arise when assessment is inadequate or inappropriate tools are utilised.
A pain-free face and a face in pain
What can you see ??
When assessing for pain ...

- **Know** your resident living with dementia
- Assess whilst **moving** if possible
- Ensure **good lighting**
- Ensure all **communication aids** are in place
- Undertake **assessment regularly** (preventatively and reactively)
- Report any changes **immediately**
- **Document** accordingly
Pain measurement scales – some options

For older people

- **The Brief Pain Inventory (BPI)**

Dementia specific

- **Pain Assessment Checklist for seniors with Limited Ability to Communicate (PACSLAC)**

- **Pain Assessment in Advanced Dementia (PAINAD) Scale**

- **The Abbey Pain Scale (Abbey et al, 2003)**
# The Abbey Pain Scale

For measurement of pain in people with dementia who cannot verbalise.

**How to use scale:** While observing the resident, score questions 1 to 6.

<table>
<thead>
<tr>
<th>Question</th>
<th>Description</th>
<th>Absent</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q1</td>
<td>Vocalisation&lt;br&gt;eg. whimpering, groaning, crying</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Q2</td>
<td>Facial expression&lt;br&gt;eg. looking tense, frowning, grimacing, looking frightened</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Q3</td>
<td>Change in body language&lt;br&gt;eg. fidgeting, rocking, guarding part of body, withdrawn</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Q4</td>
<td>Behavioural Change&lt;br&gt;eg. increased confusion, refusing to eat, alteration in usual patterns</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Q5</td>
<td>Physiological change&lt;br&gt;eg. temperature, pulse or blood pressure outside normal limits, perspiring, flushing or pallor</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Q6</td>
<td>Physical changes&lt;br&gt;eg. skin tears, pressure areas, arthritis, contractures, previous injuries</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

Add scores for 1 - 6 and record here

<table>
<thead>
<tr>
<th>Total Pain Score</th>
<th>0 - 2</th>
<th>3 - 7</th>
<th>8 - 13</th>
<th>14+</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chronic Acute</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acute on Chronic</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>


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26/10/2012
Responding to pain
Pharmacological Treatments

Evidence suggests that residents with Alzheimer’s disease are given fewer analgesics than elderly persons without dementia. **WHY??**
Pharmacological pain responses

• Nociceptive pain usually responds to simple analgesics, anti-inflammatory medications and opioid compounds together with non-pharmacological strategies such as cognitive-behavioural therapy and/or physical strategies such as heat.

• Neuropathic Pain is less responsive to conventional analgesics. Adjuvant drugs such as tricyclics antidepressants, anticonvulsants or antiarrhythmics, alone or in combination, may have a role in management.

• Short acting analgesia given prior to an activity can be effective at reducing predictable (incident) pain.
World Health Organisation (WHO) 3 step ladder

1. Mild
   - Aspirin
   - Acetaminophen
   - NSAIDs
   - ± Adjuvants

2. Moderate
   - APAP / codeine
   - APAP / hydrocodone
   - APAP / oxycodone
   - APAP / dihydrocodeine
   - Tramadol
   - ± Adjuvants

3. Severe
   - Morphine
   - Hydromorphone
   - Methadone
   - Levorphanol
   - Fentanyl
   - Oxycodone
   ± Adjuvants

Things to remember about pharmacological approaches

• Medication actions and interactions need to be seen in light of potential complications.

• Analgesic medications provide symptomatic pain relief but do not modify the underlying cause of pain.

• Regular (around the clock i.e. 24/7 ) administration of analgesia is the most effective treatment for persistent pain.

• A barrier to successful pain management is the use of “PRN” medications as a front line approach.

• Once pain is identified...assess at least fourth hourly
Hot off the press!!!

Painkillers 'may ease agitation' in dementia patients

Many dementia patients being prescribed "chemical cosh" antipsychotic drugs could be better treated with simple painkillers, research says.

• After eight weeks, there was a 17% reduction in agitation symptoms in the group being given painkillers - a greater improvement than would have been expected from treatment with antipsychotics.

• The researchers concluded that if patient's pain was properly managed, doctors could reduce the number of prescriptions for antipsychotic drugs.  
Cognitive therapies

• Despite strong scientific evidence this type of therapy rarely used in the care of older people.
• Clearly... cognitive skill is required for maximum effect.
• Some clients with early dementia may still benefit.
• Use of imagery and relaxation approaches may have a valuable effect
Physical Therapies

• Strengthening, aerobic and stretching exercises may assist preventatively and responsively.
• The application of heat may positively impact on pain (but caution in residents who may not be able to articulate if too hot)
• Pain may be due to (or made worse by) being left in the same position ...remember to change position.
• May involve collaboration with physiotherapists and or occupational therapists etc.
Complementary and Alternative Therapies

• Often used for pain relief in conjunction with orthodox medicine.
• A diversity of therapies fit into this category.
• May be beneficial if there is good communication between the practitioners and their treatments complement each other.
• Openness and knowledge of possibilities is essential to embrace complementary and alternative therapies in response to pain.
• In collaboration with treating practitioners and with consent.
Possible Discussion Points

• Do you have any examples of the use of alternative therapies within your work environment
• Dependent also on understanding of the person with dementia’s pre-morbid beliefs and practices in this area.
• Options may include Aromatherapy, Acupuncture, various forms of specialised massages, Reiki, Osteopathy, Naturopathy, Chiropractics
• TENS machine
Reflections and Evaluation
Reflection

• What could you do to change current practices within your environment to more accurately reflect some of these issues?
• What would you now advise the organisation to consider to improve pain practice?
• What factors can we control that would help us do the best job possible?
Some Additional Resources

- McClean and Cunningham, (2007) provide an excellent practice guide “pain in older people and people with dementia" which can be used as a self study guide or as facilitated training guide. Available from http://dementia.stir.ac.uk/files/PublicationsListOctober2010.pdf

- City of Hope Pain & Palliative Care Resource Center http://prc.coh.org/pain_assessment.asp

- A Booklet “Dementia information for carers, families and friends of people with severe and end stage dementia 2nd Edition is available to download at the following address. http://www.uws.edu.au/__data/assets/pdf_file/0008/7100/INFORMATION_Dementia__Web_Ready.pdf

- Canadian resource - designed to assist Long-Term Care (LTC) homes with the implementation of the Assessment and Management of Pain Best Practice Guidelines http://ltctoolkit.rnao.ca/resources/pain
Some Additional Resources (cont)

• The Australian Pain Society has addressed the issue of pain in *Pain in Residential Aged Care Facilities: Management Strategies*, (2005). Additional copies can be downloaded from the Australian Pain Society website: [www.apsoc.org.au](http://www.apsoc.org.au)


• Guidelines for a palliative Approach in residential Aged care (May 2006) The national Palliative Care Program, Prepared by Edith Cowan University, National Health and Medical research Council Available to download; [www.nhmrc.gov.au](http://www.nhmrc.gov.au)


Apel, S., Koch, S., & Fetherstonhaugh, D. (2009), Pain assessment and management for people with dementia in an acute care unit, La Trobe University as represented by the Dementia Collaborative Research Centre Carers and Consumers.


Cunningham, Colm. Maybe it’s Pain. AAA March – April 2011.


Frampton, M A. Experience assessment and management of pain in people with Dementia, Department of Psychiatry and Behavioural Sciences, University College London, Age and Ageing 2003; 32: 248–251 # Age and Ageing Vol. 32 No. 3 # 2003, British Geriatrics Society. All rights reserved.


Husebo BS, Ballard C, Aarsland D; Pain treatment of agitation in patients with dementia: a systematic review; International Journal of Geriatric Psychiatry (Feb 2011)


Acknowledgements

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Related components developed

Pain package ...now available on the DCRC website:

A series of papers on pain in people living with dementia: published in The International Journal of Older People Nursing August 2012

Dementia e-learning module on pain: