

Co-Morbid Pain and Dementia:
A Case Study as Impetus for Change

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Toward a Co-Morbid Pain and Dementia: A Case Study

There is a need for Canadian healthcare leaders and policy makers to examine the issues surrounding pain assessment and management in the institutionalized elderly. According to the Canada Health Act (Government of Canada, 1984, last amended 2012), healthcare policy should “protect, promote and restore the physical and mental well-being of residents of Canada” (p. 5), and that this includes barrier-free access to healthcare services regardless of age, health status and setting. Despite this legislation, long-term care residents with dementia and/or an inability or decreased ability to communicate are less likely to be assessed and receive treatment for pain than those without similar impairments (Horgas & Miller, 2008; Kaasalainen et al., 2007; Martin, Williams, Hadjistavropoulos, Hadjistavropoulos, & MacLean, 2005; Morrison & Sui, 2000). This reality competes with Ontario’s accepted definition of long-term care homes as places where physical and psychological needs, including comfort, are safely met and where “every resident has the right to receive care and assistance towards independence based on a restorative care philosophy to maximize independence to the greatest extent possible” (Ontario Ministry of Health and Long-Term Care [OHMLTC], p. 56). Further, the Act emphasizes that those who are unable to communicate must have pain assessed and managed using clinically appropriate tools and strategies (OHMLTC).

Pain management in long-term care should be driven by two essential principles: First, care must be based upon evidence-based practice protocols that are safe, effective, and ethically sound. Second, interprofessional approaches to pain management are essential to better manage pain in the long-term care sector

(Hadjistavropoulos, Janzen Claude, Hadjistavropoulos, Marchildon, Kaasalainen, Gallagher, & Beattie, 2011). Unfortunately, the application of these principles are significantly lacking in the care provided to those who are unable to communicate or verbally express pain due to dementia or other disorders. This issue is highly complex, thus demanding the collective attention of health care policy makers, professional and regulatory bodies, organizations and care providers to address its many challenges. The following case study describes an advanced practice nurse's (APN) approach in addressing several of the barriers associated with assessing and managing co-morbid pain and dementia in long-term care. It also emphasizes the need for a holistic, client-focused assessment and interprofessional approach to pain management in this population.

The Case

Background and Presentation

Mrs. R. is a 92-year-old female resident of a long-term care facility in Ontario, Canada. She is diagnosed as having late stage Alzheimer's type dementia. Due to agitation, she was originally managed with resperidone (Resperdal) 0.25 mg at bedtime and quetiapine (Seroquel) 100 mg at bedtime and in the morning. The order for discomfort was acetaminophen (Tylenol) 500 mg 3 times daily. Her agitation had increased to aggressiveness and irritability over time, and this challenged the provision of nursing care. Behaviours including slapping and biting of staff and family members and the resident's repeated banging of her walker into walls.

Assessment

With family and nursing staff present, an APN, skilled in palliative nursing, conducted a history and physical assessment on Mrs. R. The interview was emotionally

charged, and included gentle and quiet reminiscence by the APN of the resident's former ability to raise four children and of the many contributions she had made to her community. Mrs. R. was unable to verbalize a response, but had a few quiet tears and smiles while riveting her eyes on the APN, and responding to her gentle touch. Her responses astonished both family and staff. During the interview, a personal support worker with a pleasant, but very loud voice, entered the room with some water. Mrs. R. had a strong startle response and was immediately agitated. The APN suggested a quiet environment in which to continue the assessment.

The history of her past illnesses revealed: no cardiovascular or gastrointestinal problems; no reported past emotional problems; bilateral cataract removal with good vision; no hearing deficit; total left hip arthroplasty with history of back pain and osteoarthritis. Urinary status was confirmed by urinalysis and blood work, and no abnormal findings were noted. A dentist routinely managed Mrs. R's dental and oral care. The APN noted that this resident had a severe kyphoscoliosis and distinct favouring of the left hip and leg. This was prominent on ambulation. The social history revealed her preferences related to music, physical and recreational activities. Mrs. R.'s family was a great resource for information and care suggestions.

Suspicious of an unnoticed and unreported level of pain, the APN used the Abbey Pain Scale (Abbey et al., 2004) in an attempt to measure her actual pain level (Figure 1). This scale was developed to measure pain in people with late-stage dementia (Abbey et al.). It can be administered in one minute, and used by a variety of health care providers (Abbey et al.). Mrs. R. scored a total of 12 points and the scale indicates that a score of 8-13 suggests moderate pain. Since the scale under the

behaviour 'vocalization' coded a numeric value of '0' for absent vocalization, a question is proposed: Would Mrs. R.'s actual score be higher if she was able to vocalize her pain?

Pain Management Interventions and Outcomes

Based on findings, the APN made a preemptive decision to request that Mrs. R. be tried on a very low dose of hydromorphone (Dilaudid) 0.25 mg every four to six hours. Two days later on a re-visit, the APN found Mrs. R. less aggressive and moving about more easily. The physician increased hydromorphone to 0.5 mg every 6 hours, and this was tried for another week. The nursing staff reported that her care was more manageable and that she had resumed eating. Her family began to take her for walks outside and brief car trips.

Mrs. R. began to refuse all medications by mouth even in liquid or food. Risperidone was discontinued and Seroquel was reduced to 25 mg in the morning, and this was refused. The APN then requested the hydromorphone be given subcutaneously in situ, at 0.25 mg every four hours. Two weeks later, Mrs. R. was started on a fentanyl patch (Duragesic) giving her a dose of 12.5 mcg and changed every 72 hours. This did not adequately address her pain, and the dose was increased to 25 mcg within 8 days.

Over several months, this dose was titrated up to 100 mcg and Mrs. R. began taking longer walks in the park and started to speak in three to four word sentences. For the infrequent episodes of aggression demonstrated during a noisy interaction or abrupt movement of her person, Mrs. R. is now managed with trazadone (Desyrel) 12.5 mg twice a day and 50 mg at bedtime. Risperidone 0.25 mg is given only for extreme

aggression and bi-weekly baths, and haloperidol (Haldol) 1-2 mg intramuscular if needed for agitation or aggression that cannot be settled. At present, Mrs. R. only becomes agitated if staff is unknown to her, or is overly assertive or aggressive in care activities, including giving medications, bathing, or assisting with feeding.

Discussion

Pharmacological pain management and a quiet, soothing approach to care were the most significant factors in improving Mrs. R.'s quality of life. This is consistent with research that highlights a need for both pharmacological and non-pharmacological approaches that are individualized to the resident (Ferrell & Whiteman, 2003; Gibson, Farrell, Katz & Helme, 1996; Horgas & Elliott, 2004). This case study reflects the need for comprehensive evidence-based approaches to best assess and manage the pain of individuals who are challenged to communicate their symptoms. Although this gap that is reported extensively in the literature (Cohen-Mansfield & Lipson, 2002; Cohen-Mansfield & Lipson, 2008; Fuchs-Lacelle, Hadjistavropoulos, & Lix, 2008; Horgas & Elliott, 2004), many barriers and challenges persist.

To understand the many factors that influence co-morbid pain and dementia among persons with dementia who are unable to communicate, we sought research funding from the deVeber Institute for Bioethics and Social Research in Toronto, Ontario. The deVeber Institute provided financial and in kind support to gather and synthesize the literature related to this issue. As a result, a summer intern was hired to conduct a comprehensive search of the research literature. Additional special donations enabled the research to proceed, and a second paper, a systematic review of the literature is in process. The latter paper highlights the factors that influence

interprofessional assessment of pain in long-term care facilities. Our exploration of the research highlights the longstanding challenges related to identifying and managing pain in persons with communication problems or inability to communicate at all. It also reveals several evidence-based interventions that were initiated by the APN, and were effective in Mrs. R.'s case.

According to experts, “the full continuum of clinical care, including pain assessment and management, of older adult residents in LTC [long-term care] facilities” can be managed by a nurse practitioner (Hadjistavropoulos et al., 2011, p. 42). In this case, the APN did assume a leadership role in developing and monitoring the plan of care. Interventions were recommended by the APN and vetted with the physician, nurses, other health care staff, and family. Ongoing evaluation also included feedback from all team members.

The APN began with a thorough holistic health history of the resident that ruled out other potential causes of the resident's aggressive behaviours. Once this was determined, pain medication was administered with follow-up assessments to evaluate effectiveness of the plan. This care approach is supported by the literature (Horgas & Elliott, 2004; Weiner & Hanlon, 2001). Also consistent with the literature, Mrs. R.'s pain medication was scheduled (Monroe, Carter, Feldt, Tolley & Cowan, 2011), and family members were consulted in the plan of care (Buffam & Haberfelde, 2007; Cohen-Mansfield, 2002).

In the case of Mrs. R., continuous monitoring continues to be required; yet, it is hampered by the increased illness acuity of residents and a lack of resources. In particular, there are staffing shortages; lack of RN staff with the required education; no

APN on the premises; and minimal medical coverage. Again, these findings are highlighted in the published literature (Carder, 2011; Chang et al., 2009; Cohen-Mansfield, Thein, Marx, & Dakheel-Ali, 2012; Hadjistavropoulos et al., 2011).

With the current funding model for long-term care in Ontario, these resources are very difficult to secure. Chronic underfunding has resulted in staffing patterns that are characterized by insufficient numbers of registered nurses and registered practical nurses, and the delivery of frontline care by personal support workers who are unregulated and lack the theoretical knowledge to assess and manage pain. This human resources deficit also perpetuates a rush to get work completed without attention to the needs of residents that are highly complex. Lack of education can also result in communication patterns by staff members that are ineffective, and detrimental to wellbeing. That is, loud speech by health care providers can become habitual, and used with all residents who may or may not have actual hearing deficits. In Mrs. R.'s situation, the noisiness of the corridors, staff, visitors and other residents provide a fertile ground for confusion, irritability, and ultimately increased aggression.

As illustrated by this case study, the preemptive use of opioids, while risky, can be very helpful in the treatment of pain that is manifested by aggression in late stage dementia. Nevertheless, many healthcare providers are hesitant to prescribe and administer opioid drugs to older adults (Cohen-Mansfield & Lipson, 2001; Kassalainen et al., 2007). The collaboration of all care providers, including family, is required to comprehensively assess and evaluate the outcomes of pain management interventions, especially the use of opioids.

Conclusion

While it is difficult to distinguish all of the precursors to agitation and aggressive behaviours among older adults with dementia, the literature supports that pain and aggression are often interrelated (Davis & Srivastava, 2003). This case study summarizes a care approach that resulted in improved outcomes for one long-term care resident. Although the literature favours an interprofessional approach (Hadjistavropoulos et al., 2011), future research is needed to comprehensively understand and address the systemic challenges.

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

Name of resident:

Name and designation of person completing the scale:

Date: **Time:**

Latest pain relief given was.....athrs.

Q1.	Vocalisation eg. whimpering, groaning, crying <i>Absent 0 Mild 1 Moderate 2 Severe 3</i>	Q1	<input style="width: 40px; height: 30px;" type="text"/>
Q2.	Facial expression eg: looking tense, frowning grimacing, looking frightened <i>Absent 0 Mild 1 Moderate 2 Severe 3</i>	Q2	<input style="width: 40px; height: 30px;" type="text"/>
Q3.	Change in body language eg: fidgeting, rocking, guarding part of body, withdrawn <i>Absent 0 Mild 1 Moderate 2 Severe 3</i>	Q3	<input style="width: 40px; height: 30px;" type="text"/>
Q4.	Behavioural Change eg: increased confusion, refusing to eat, alteration in usual patterns <i>Absent 0 Mild 1 Moderate 2 Severe 3</i>	Q4	<input style="width: 40px; height: 30px;" type="text"/>
Q5.	Physiological change eg: temperature, pulse or blood pressure outside normal limits, perspiring, flushing or pallor <i>Absent 0 Mild 1 Moderate 2 Severe 3</i>	Q5	<input style="width: 40px; height: 30px;" type="text"/>
Q6.	Physical changes eg: skin tears, pressure areas, arthritis, contractures, previous injuries. <i>Absent 0 Mild 1 Moderate 2 Severe 3</i>	Q6	<input style="width: 40px; height: 30px;" type="text"/>

Add scores for 1 – 6 and record here ➔ **Total Pain Score**

Now tick the box that matches the **Total Pain Score** ➔

0 – 2 No pain	3 – 7 Mild	8 – 13 Moderate	14+ Severe
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Finally, tick the box which matches the type of pain ➔

Chronic	Acute	Acute on Chronic
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Dementia Care Australia Pty Ltd
 Website: www.dementiacareaustralia.com

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Figure 1.

References

- Abbey, J., De Bellis, A., Piller, N., Esterman, A., Giles, L., Parker, D., & Lowcay, B. (2004). The Abbey pain scale: a 1-minute numerical indicator for people with end-stage dementia. *International Journal of Palliative Nursing*, *10*(1), 6-13.
- Buffam, M.D., & Haberfelde, M. (2007). Moving to new settings: Pilot study of families' perceptions of professional caregivers' pain management in persons with dementia. *Journal of Rehabilitation Research & Development*, *44*(2), 295-304.
- Carder, P.C. (2011). "Learning about your residents": How assisted living residence medication aides decide to administer pro re nata medications to persons with dementia. *The Gerontologist*, *52*(1), 46-55. doi:10.1093/geront/gnr099
- Chang E, Daly J, Johnson A, Harrison K, Easterbrook S, Bidewell J, Stewart H, Noel M, & Hancock K. (2009). Challenges for professional care of advanced dementia. *International Journal of Nursing Practice*, *15*, 41–47
- Cohen-Mansfield, J. (2002). Relatives' Assessment of Pain in Cognitively Impaired Nursing Home Residents, *Journal of Pain and Symptom Management*, *24*(6) Pp
- Cohen-Mansfield, J., & Lipson, S. (2008). The utility of pain assessment for analgesic use in persons with dementia. *Pain*, *134*, 16–23
- Cohen-Mansfield, J., Thein, K., Marx, M.S., & Dakheel-Ali, M. (2012). What are the barriers to performing nonpharmacological interventions for behavioral symptoms in the nursing home? *Journal of the American Medical Directors Association*, *13*, 400 – 405. doi:10.1016/j.jamda.2011.07.006
- Davis MP, Srivastava M. (2003). Demographics, assessment and management of pain in the elderly. *Drugs and Aging*, *20*(1), 23–57.
- Ferrell BA, Whiteman JE. (2003). Pain. In: Morrison RS, Meier DE, Capello C, editors. *Geriatric Palliative Care*. pp. 205-229. New York: Oxford University Press.
- Fuchs-Lacelle, S., Hadjistavropoulos, T., & Lix, L. (2008). Pain assessment as intervention. A study of older adults with severe dementia. *Clinical Journal of Pain*, *24*, 697–707.
- Gibson S, Farrell M, Katz B, Helme R. (1996). Multi-disciplinary management of chronic nonmalignant pain in older adults. In: Ferrell BR, Ferrell BA (eds), pp. 91-99. editors. Seattle: IASP Press.
- Government of Canada. (1984, last amended 2012). The Canada Health Act. Available at: <http://laws-lois.justice.gc.ca/PDF/C-6.pdf>

- Hadjistavropoulos, T., Janzen Claude, J., Hadjistavropoulos, H., Marchildon, G., Kaasalainen, S., Gallagher, R., & Beattie, B.L. (2011). Stakeholder opinions on a transformational model of pain management. *Journal of Gerontological Nursing*,
- Horgas & Elliott (2004). Pain assessment and management in persons with dementia. *Nursing Clinics of North America*, 39, 593-606.
- Kaasalainen, S., Coker, E., Dolovich, L., Papaioannou, A., Hadjistavropoulos, T., Emili, A., & Ploeg, J. (2007). Pain management decision making among long-term care physicians and nurses. *Western Journal of Nursing Research*, 29(5), 561-580.
- Ontario Ministry of Health and Long-Term Care (2013). *Long-Term Care Homes Act, 2007 – O. Reg. 79/10*. Available at: http://www.e-laws.gov.on.ca/html/source/regs/english/2010/elaws_src_regs_r10079_e.htm
- Monroe, T., Carter M., Feldt K., Tolley B., & Cowan R.L. (2012). Assessing advanced cancer pain in older adults with dementia at the end-of-life. *Journal of Advanced Nursing* 68(9), 2070–2078. doi: 10.1111/j.1365-2648.2011.05929.x
- Weiner DK, Hanlon JT. Pain in nursing home residents: management strategies. *Drugs Aging* 2001;18(1):13–29.