People with dementia need better pain management

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Any notion that people with dementia feel less pain should be dismissed. Chronic pain is at least as prevalent among people with dementia (up to half) as it is among other elderly people.[1–3] Further, its frequency does not change with the severity of cognitive impairment.[4] However, chronic pain is typically underdetected in this population and, thus, is poorly managed.[5,6] This failure to detect is most apparent among those with severe cognitive impairment.[6] Closing this gap in care will be of increasing importance because, in the coming decades, one quarter of Canada's population is projected to be seniors, over a million of whom will have dementia.

Pain in older people is mainly due to degenerative disease of the joints and spine, neuropathic pain, fractures and cancer. It is associated with functional impairment, mood changes, sleep disturbance, poor appetite and increased health care use. Pain is perceived differently by older people because small pain fibres are reduced in number. The result is a higher pain threshold to peripheral noxious stimuli. However, they also tolerate pain less well than younger people because of a decline in endogenous opioid receptors in the brain.[7] There is also emerging evidence for age-related, postinjury hypersensitization and hyperalgesia.[7] Because it is challenging to research pain in people with dementia, the extent to which this new information applies is unclear, particularly to people with severe dementia, but the weight of evidence indicates that they suffer in the same way younger people do.

Pain is a symptom, a matter of subjective evaluation and report, but people with dementia may find it difficult to report. However, there are methods that can be used to detect and survey pain and its intensity, at least for those with moderate dementia. These methods use verbal and visual self-report scales, face pictures and bedside observation of posture, protection, facial expression and behaviour during daily activities.[4,5] Other methods that are being studied for assessing pain in critically ill adults who cannot self-report pain[8] hold promise for pain management in noncommunicative people with dementia.

People with dementia are less able to tolerate opioids and other systemic chemical analgesics at a dose and frequency that will bring pain relief. Their atrophied bodies have a smaller volume of distribution. An atrophied brain is more susceptible to adverse cognitive effects of centrally acting analgesics. An aged liver is less efficient at metabolizing narcotics, and aged kidneys are slower to excrete metabolites. Accompanying comorbidities require the use of other types of medications, a setting for medication interactions. For these reasons, some patients require the expertise of pain medicine specialists, who are in short supply at this time. Other approaches such as physical and behavioural therapy, massage, nerve blocks and counter-stimulation show promise and require more study. We also need to do more work on establishing how to measure patient-relevant outcomes. Given this need for improved knowledge, it is of concern that the very elderly, residents of long-term care facilities and people with dementia are routinely excluded from randomized trials.

The highly personal and day-to-day aspects of effective pain assessment and control for people with dementia suggest that the following features of bedside care are needed. The health care provider assigned to this task (typically the nurse) should be one who knows the patient well and most regularly provides bedside care. The provider should be well-trained and supported in modern methods of assessment and interventions for pain. The provider should also be accorded, within protocol limits, more licence to alter the frequency and dosage of particular pain treatments.

Based on what we already know, it seems clear that meeting the need for pain relief in people with dementia will require more skilled care at the bedside. What is needed most, however, is a person-centred and attentive approach. A person with dementia may be losing cognitive ability, but some aspects of personhood must still be respected — namely dignity, life-story and family connection.[3] To this list we should add perception of pain and suffering. We have sufficient evidence and a professional obligation to control the pain of people with dementia. A person with dementia is not a nonperson and should not be cared for as though this were the case. To the extent that we as caregivers treat a person with dementia as a nonperson, the therapeutic relationship and the personhood of the caregiver are also diminished.[3]

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