Pay Attention to My Pain: Understanding Pain-related Behaviours in Residents with Dementia

I'm trying to show you I hurt...pay attention to my pain!

Dementia-related behaviours that pose a challenge to long term care staff are often labelled as being problematic. Biological and psychological symptoms of dementia—including 'disruptive behaviour,' 'difficult behaviour,' 'problem behaviour,' 'excessive behaviour' and 'challenging behaviour'—have all been used to describe the way people with dementia try to communicate their needs. Referring to these behaviours as a 'problem' to be 'managed' has led to attempts to develop cookie-cutter pathways or magic bullet pharmacological answers. Not surprisingly, this approach has failed and there is an increasing understanding that a different approach is necessary for dementia-related behaviours.

TABLE 1

Background needs/factors	Here and now needs/triggers	Behavioural expression of need
Cognitive strengths and challenges	Emotional needs	Examples: aggressiveness, calling out, pacing
Psychiatric illness/ substance misuse	Physiological needs	
General health issues	Psychiatric needs	
Medication issues	Physical environment	
Psychosocial	Social environment	
Personality style	Spiritual needs	Adapted from Algase and Beck, 1996.

The need-driven dementia-compromised behaviour model.

What does a 'problem' behaviour mean from the resident's perspective?

Taking a person-centred perspective, it is necessary to ask what these 'disruptive' behaviours mean from the view of the person with dementia. The caregiver may describe a behaviour as disruptive or excessive, but perhaps it is the resident's only means of communicating a need that is being overlooked.

In 1996, Donna Algase and colleagues developed the 'need-driven dementia-compromised behaviour' model (Table 1) to help caregivers understand the meanings behind behaviours and the needs a person may be trying to communicate. Instead of labelling a behaviour as being 'problematic,' caregivers are encouraged to try to understand it as the resident's best means of informing the caregiver of a need that he or she cannot voice directly. This places the responsibility on the caregiver to determine the resident's needs and respond to them.

The conceptual model created by Algase et al. suggests that background factors may precipitate need-driven behaviours (NDBs). In addition, proximal or 'here and now' factors, described as the 'more fluid or fluctuating aspects of the immediate physical and social and emotional environment,' also contribute to behaviour.

Background and proximal factors

Background factors describe the conditions that put the resident at risk for NDBs. They can relate to neurological, cognitive, general health, psychiatric, life history and/or personality issues. They allow caregivers to identify key aspects of a person that may be functioning in combination with events in the proximal 'here and now' setting to create NDBs. The problem-solving abilities and communication challenges that arise later in dementia (with expressive and or receptive aphasia) are two major cognitive contributors to NDBs.

Examples of proximal factors leading to NDBs are:

- physical factors, such as temperature (feeling too hot or too cold), discomfort in positioning or clothing and/or care that precipitates pain;
- a physical environment that is either too stimulating or too depriving of stimuli; and/or
- social interactions that are rushed or disrespectful (e.g., patronizing, bossy or objectifying) or that outpace the resident's abilities (e.g., moving or talking too quickly).

In assessing residents with dementia and NDBs, it is best to regard the situation as a puzzle that requires solving. Caregivers must look for clues in each of the background and proximal areas described above.

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Assessment and treatment of pain for residents in long term care

Pain is one of the most commonly overlooked precipitants of NDBs, especially in residents who have an illness that compromises verbal communication.

In terms of examining the background factors, it is necessary to look at:

- medical history and pain related to chronic conditions (including the resident's history of analgesic use);
- the emergence of new pain-inducing related conditions;
- pain tolerance and usual pain behaviour;
- psychiatric issues (e.g., comorbid depression); and
- personality factors that might influence pain-related behaviour.

Older adults have a much higher prevalence of pain than the general population, with estimates of up to 80 per cent prevalence in residential care. Multiple body sites can be painful. Pain is often related to the musculoskeletal system due to arthritis and degenerative changes, but many comorbid medical conditions—such as congestive heart failure, chronic obstructive pulmonary disease and renal disease—do cause pain and should also be taken into account.

A review of the medical history for painful conditions and past use of analgesics is essential. Family members who have been involved in care might be able to contribute information from the past, particularly about previous pain-related behaviour. In general, family members are good at identifying pain in loved ones, but they tend to overestimate the severity of the pain. In contrast, health care providers tend to underestimate pain.

Documenting baseline behaviour requires discussions with staff who know the usual behaviour of the resident. If the resident is new to a long term care home—or if staff are unfamiliar with the individual—then use of a checklist of non-verbal behaviours can help staff identify and monitor behaviours, and analgesics and other medications can be trialled. Many scales for behaviour monitoring have been validated and tested in residential care, but the key issue is to track the behaviour both before and after an intervention.

Proximal factors that may contribute to pain-related behaviours include inappropriate seating or clothing. In addition, pain can be induced during care activities such as:

- dressing;
- wound dressing changes; and/or
- bathing.

In these situations, care may be provided without thought to how certain movements can create pain for a resident with dementia. Lack of attention to pain issues during regular care can actually put caregivers in danger if, for example, residents attempt to protect themselves from the pain-inducing activity by hitting caregivers or pushing them away.

It is vital to keep in mind that the behaviour being monitored is a sign of distress and that there may be multiple simultane-

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ous causes for the distress. Fear of a situation (e.g., bathing, perineal care), fear of pain and decreased impulse control can all coexist with pain. In addition, other symptoms, such as shortness of breath, may induce the same distress behaviour. Thus, a systematic assessment and comprehensive care plan are necessary to identify and address all of the unmet needs that might be contributing to a particular situation.

Pharmacological interventions for pain in long term care

The American Geriatrics Society has released an updated version of its clinical practice guideline on the 'Pharmacological Management of Persistent Pain in Older Persons' (www.americangeriatrics.org/education/pharm_management.shtml). This updated version calls for a trial of acetaminophen. If the pain persists, then the addition of an opioid rather than a non-steroidal anti-inflammatory drug (NSAID) is suggested because of the risk of renal failure, bleeding and cardiovascular disease with NSAIDs in older adults.

Opioids

There is a paucity of studies comparing different opioids in older adults. One certainty is that there is significant interindividual variation with all opioids. It is therefore important to individually select and titrate opioids for pain relief and shortness of breath. The opioids of choice in frail residents are those that have no significant active metabolites, such as oxycodone, fentanyl and methadone. Active metabolites are thought to contribute to opioid-induced neurotoxicity, a syndrome that ranges from drowsiness to myoclonus, hallucinations, delirium and seizures. Hydromorphone is preferred over morphine in older adults and those with renal failure because its active metabolites are cleared relatively quickly.

Long-acting opioids are preferable to short-acting drugs because they provide long-lasting relief, fewer side effects and less administration time. Ideally, a resident would start on a short-acting opioid and be titrated up to the optimal dose before switching to a long-acting opioid, but this requires greater staffing levels than are found in most long term care homes.

Long-acting opioids exist in low enough doses to initiate these formulations in frail residents. One of these is oxycodone sustained release (SR), which comes in a 5 mg strength. When this dose is given every 12 hours, it is equivalent to three Tylenol #3 tablets over a 24-hour period. This current formulation must be swallowed whole, which is a barrier for residents with dysphagia.

Another option is the fentanyl transdermal patch, which can be started at a very low dose by exposing only one half of the 12 mcg patch to the skin. This is approximately equivalent to five Tylenol #3 tablets per 24-hour period.

Methadone can be an ideal opioid for frail residents, providing the physician is familiar with its pharmacology. It can be

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started at a dose of 1 mg every 12 hours and is equivalent to about four Tylenol #3 tablets per 24 hours. It must be started at a very low dose and up-titrated no more frequently than once weekly. It is essential to have appropriate education and mentoring in using methadone safely.

Frequent reassessment is necessary as it is rare that the initial dose of an analgesic will result in satisfactory pain control. Nowhere else is the maxim 'start low and go slow' more important than for opioid use in frail older residents. If this advice is followed, however, then opioids are safe medications for the treatment of pain and shortness of breath in all older adults, including those with cardiopulmonary disease.

Adjuvant medications

Adjuvant medications should always be considered, particularly as much of the pain in older adults involves a neuropathic component that requires adjuvant medications in addition to analgesics. Although anticonvulsants are effective in treating neuropathic pain, older adults often cannot tolerate the side effects enough to be titrated up to a therapeutic dose. Antidepressants are often a better choice as an adjuvant because they will benefit mood, sleep and appetite in addition to addressing pain.

Antidepressants with noradrenalin and serotonin receptor action are thought to work best for pain, although tricyclic antidepressants have the most evidence. Because many older adults have cardiac conditions or do not tolerate the side effects of tricyclic antidepressants, however, the newer multi-receptor drugs such as mirtazepine, venlafaxine and duloxetine are probably the better choices.

Analgesic trials

If there is not compelling 'evidence' that a resident's behaviour is pain related, a trial of analgesics should be considered when other non-pharmacological and pharmacological therapies have failed. Giving acetaminophen alone does not provide an adequate trial of analgesics, as many older adults will have moderate to severe pain. If the acetaminophen has no effect on behaviour then a low-dose long-acting opioid should be added and titrated slowly. If the behaviour is pain related then caregivers will see a positive change in the resident. If it is not, the side effects of the opioid will be most evident and there will be drowsiness with the ongoing behaviour (unless there is significant sedation).

It is important to titrate one medication/therapy at a time so that a change can be clearly attributed to the intervention.

Studies demonstrate that the treatment of pain in older adults with dementia using opioids results in improved social interaction and performance of activities of daily living, with no decline in cognitive function. The presumption of pain and subsequent treatment in dementia-compromised NDBs should be a strategy used by all clinicians working in residential care. LTC

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