

Table 2: Summary of studies

Author (s) and year	Country of origin	Title of paper	Aim(s)	Methods	Findings	Conclusions / recommendations	Limitations
Barry, H., Parsons, C., Passmore, P., Hughes, C 2012	UK: Northern Ireland	An exploration of nursing home managers knowledge of and attitudes towards the management of pain in residents with dementia	Aims (1) to explore knowledge, attitudes and beliefs of nursing home managers about pain assessment and management in residents with dementia. (2) to determine effect of respondent demographic characteristics.	Postal questionnaire survey to 96% nursing home managers in northern Ireland. Response rate: 39%; n=96	Demographics: Mainly UK educated, female and experienced. Most not received recent education on pain in dementia. Generally good knowledge but expressed challenges around pain assessment and concerns about use of opioids. 8.3% felt resident with dementia could accurately self-report pain. Only 60% used pain treatment guidelines in the home.	Ambiguities among nursing home managers about pain assessment and management. Need for clear care standards as well as guidance and training for nursing staff.	Low response rate. In one small country.
Brorson, H., Plymoth, H., Ornon, K. and Bolmsjo, I., 2014.	Southern Sweden	Pain relief at the end of life: Nurses' experiences regarding end-of-life pain relief in patients with dementia.	To determined what nurses experience when providing pain management during end-of-life care in dementia patients.	Semi structured interviews (n=7) nurses	Nurses experienced difficulties regarding pain relief. Experienced difficulties communication with patient. (n=3) asked relatives. Use of pain assessment tools Non-pharmacological options for pain relief also worked.	Knowing patients can enable adequate pain management this is gained via experience. Knowledge on pain assessment tools can facilitate assessment.	Interviewer encouraged nurses to recall specific events but not all were able to remember. This may have affected depth of results. Small sample with just women. possibly not be transferable to other settings. Possibly not representative as the nurses volunteered.
Cohen-Mansfield, J., 2014	UK	Even with regular use of an observational scale to assess pain among nursing home residents with dementia, pain-relieving interventions are not	To examine the implementation of systematic pain observations protocol by nursing staff and its impact on analgesic medication used in people with dementia.	6 nurses observed using PACSLAC on 22 nursing home residents over 6 weeks. Staff interviewed for feedback on the protocol.	Nurses preferred non-pharmacological interventions. Less than 65% of nurses were compliant with filling out the datasheet. Half who discovered pain fail to use any interventions.	More training and education around the use of PACSLAC. More training on pharmacological interventions. More training and education by palliative care or dementia	Small sample size. Low response rate, not all the nurses were compliant.

		frequently used.			Limited understanding on pain cues.	specialists should be implemented.	
De Witt Jansen, B., Brazil, K., Passmore, P., Buchanan, H., Maxwell, D., Mellpatrick, S., Morgan, S. M., Watson, M. and Parsons, C., 2016.	UK	Nurses' experiences of pain management for people with advanced dementia approaching the end of life: a qualitative study.	Explore hospice, acute care and nursing home nurses' experience on pain management for people with advanced dementia in end-of-life.	Semi structured interviews Thematic analysis. (n=24) nurses	More training required in some settings, some nurses had no training in dementia or the management of pain. Nurses felt this was vital. Analgesia training needed. Knowledge and skills enable pain management in end-of-life dementia care.	Inequality of training is a concern. More knowledge and skills needed.	50% of study was nursing homes. Acute care nurses from elderly units from a teaching hospital, likely to display more awareness of dementia pain.
De Witt Jansen, B., Brazil, K., Passmore, P., Buchanan, H., Maxwell, D., Mellpatrick, S., Morgan, S. M., Watson, M. and Parsons, C., 2018.	UK	"A tool doesn't add anything". The importance of added value: Use of observational pain tools with patients with advanced dementia approaching the end of life—a qualitative study of physician and nurse experiences and perspectives.	Explore hospice, secondary and primary care physicians and nurses use of OPTs with dying dementia patients.	Semi structured interviews (n=24)	Barriers in using pain assessment tools. Found it difficult observing patients' behaviours and nonverbal cues. Unsure if behaviour change was a sign of pain. More skills, training and knowledge was deemed essential.	A need for ongoing training is required.	Self-selecting sample, able to discuss their frank opinions and perspectives. Recruited via index contacts.
Lichtner, V., Dowding, D., Allock, N., Keady, J., Sampson, E. L., Briggs, M., Corbett, A., James, K., Lasrado, R., Swarbrick, C., Closs, S. J., 2016	England and Scotland	The assessment and management of pain in patients with dementia in hospital setting: a multi-case exploratory study from a decision-making perspective.	To investigate how pain is recognised, assessed and managed in patients with dementia in a range of acute hospital wards.	Mixed methods Semi-structured interviews. Staff and carers. (n=31) participants observed Audits of patient records Selection theoretically driven.	Communication – relied on self-report. Communication barriers due to cognitive impairment. Poor understanding of behavioural cues. Lack of time with patient / overworked staff. Relied on relatives to determine patients' pain Lack of documentation Lack of knowledge on dementia and medication. Abby pain scale recommended but not used.	Observational pain assessment tools becoming more essential. Knowledge about patient can help. More time.	Small number of interviewed included. Finding mainly based on wards which rely on paper-based documentation. Limited data on clinicians' views and reasons for not using pain assessment tools.

<p>Midtbust, M. H., Alnes, R. E., Gjengedal, E. and Lykkeslet, E., 2018</p>	<p>Norway</p>	<p>A painful experience of limited understanding: healthcare professionals' experiences with palliative care of people with severe dementia in Norwegian nursing homes.</p>	<p>To explore and increase knowledge of health professions' experiences with palliative care to people with severe dementia in nursing homes.</p>	<p>Phenomenological research approach In-depth Interviews (n=20) health professionals (nurses)</p>	<p>Nurses found looking after dementia patients painful experience due a lack of understanding of individuals when they are unable to communicate. Struggled to find cause of patients pain. Recognise change of behaviour may indicate pain. Cooperation with relatives is crucial. Non-pharmacological interventions help as well as analgesia.</p>	<p>Dementia patients are vulnerable due to inability to express pain. Limited understanding of pain relief Further research is required. Close cooperation with relatives is essential.</p>	<p>Information about the study was given to participants before interviews were varying quality. Management team in nursing home were asked to recruit participants.</p>
<p>Monroe, T., Carter, M., Feldt, K., Tolley, B. and Cowan, R. L., 2012</p>	<p>US</p>	<p>Assessing advanced cancer pain in older adults with dementia at the end-of-life.</p>	<p>To assess advance cancer pain in older adults with dementia at the end-of-life.</p>	<p>Retrospective between groups cross sectional study.</p>	<p>As Alzheimer's worsens observational behaviours appeared to diminish. DBS is cannot identify pain in server Alzheimer's. Alzheimer's alters pain related behaviours or sentinel nervous system no longer processes and interprets signals. Caution should be taken with PRN medication Scheduled analgesics should be given.</p>	<p>Direct observations of pain management standard of care but as Alzheimer's worsen pain behaviours diminish, therefore not useful in Alzheimer's patients. New methods are needed in identifying pain. Scheduled analgesics advisable.</p>	<p>Small sample only based in US.</p>