

Title

Are there Links between Pain and Agitation in Residents with Dementia Living in Nursing Homes – a review of the literature?

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ABSTRACT –

Between 30-60% of residents of nursing homes with late stage dementia suffer with pain daily and this is thought to be due to the inability to communicate their needs. The purpose of this literature review is to analyse research to identify if there are links between pain and agitation. Three themes emerged when analysing the papers in relation to links with pain and agitation: - behavioural change that could be associated with pain, undertreating of pain and pain assessment tools. Drawing upon the findings it can be suggested that pain could be a factor that is associated with agitated behaviour, however, there needs to be further research that determines cause and effect.

Introduction

Dementia is a clinical syndrome which effects mental function; this includes language impairment, unusual behaviour and psychiatric symptoms (National Institute of Health and Care Excellence) (NICE) (2016). Dementia is a worldwide condition and the World Health Organisation (2016) states that 47.5 million people have dementia with 7.7 million new cases each year. According to Selbaek et al (2008) 80 percent of nursing home residents have dementia. Furthermore Kunik et al (2007) states that 50 – 80 percent of nursing home residents with cognitive impairments, where a significant proportion will have a dementia diagnosis, display agitation or aggression. Disruptive behaviours, such as agitation and aggression, are problematic because they are related to injuries and hospitalisation (Kunik et al 2010). Ahn and Horgas (2013) states that it is important to manage and treat the possible causes of agitated behaviour, to reduce the distress or residents, family and staff

It has been highlighted that 30-60% of residents that have late stage dementia suffer from daily pain (Achterberg et al 2010; Sandvik et al 2014 and van Dalen-Kok et al 2015). Research suggests that this could be due to losing the ability to express pain through communication (Horgas et al 2009). This could result in pain being expressed through behaviours that are disruptive such as, aggression. There have been recent studies that believe that pain may contribute to aggressive symptoms (Norton et al 2010 and Kunik et al 2010) however Huesbo et al (2011) found that pain management did not reduce agitation. van Dalen-Kok et al's (2015) review, conducted in 2013, looked at the association between pain and behaviour and noted that it is complicated and warrants additional evaluation. Further understanding of the relationship between these distressing symptoms and pain is evidently required. This literature review will look at recent research undertaken in nursing homes to see whether further links can be made between pain and agitation in people with dementia.

Methodology

The literature review explores research investigating a link between pain and behaviour in people with dementia, living in nursing homes.

A systematic search of the following databases was undertaken in November 2016:- psychINFO, CINAHL, MEDLINE, Science Direct and socINDEX. Boolean phrases (or, and, not) were used in addition with key search terms to identify relevant research (see table 1).

Table 1: Search terms and inclusion/exclusion criteria

Search Terms
Analgesia OR pain management OR pain control OR pain relief OR pain

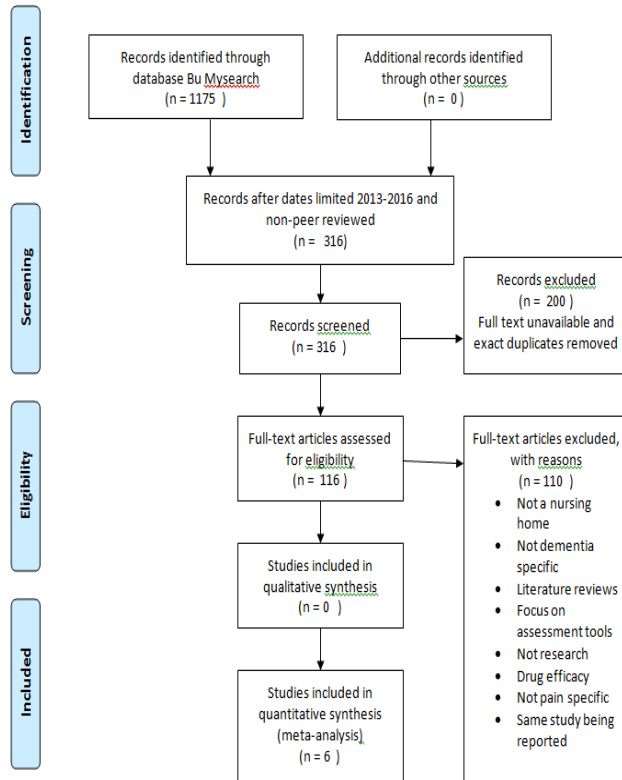
AND Dementia	
AND Agitation OR agitated OR aggression OR aggressive OR behaviour OR behavioural	
AND Care home OR nursing home OR care facility OR hospital OR ward	
Inclusion and Exclusion Criteria	
Inclusion Dementia diagnosis Nursing home English language 2013 - 2016 Peer reviewed literature	Exclusion Hospital and own home setting Unable to access News reports, commentaries, initiatives. Cognitive impairment Delirium Literature reviews

Search terms were entered and 1175 papers were identified. Publication dates were limited to 2013-2016 (n =400), because van Dalen-Kok et al (2015) conducted a similar review in 2013. Non peer reviewed papers were eliminated as Hames (2007) suggests that peer reviewed papers are critically assessed by external experts which ensures quality and validity before being published, (n =316).Removal of non-full texts and exact duplicates left 116 papers for full review. Using the exclusion criteria stated in figure 1 and table 1 a further 109 articles were removed.

The remaining six papers were assessed using critical appraisal tools (Critical Appraisal Skills Programme (CASP) 2013 and Moule et al 2003) (see appendix 1 for an overview of the papers) .Then a thematic analysis on the final papers selected in the review was undertaken and themes around the relationship between pain and agitation identified.

Figure 2 PRISMA flow diagram

PRISMA Flow Diagram



Findings

Three themes emerged from the six papers in relation to the links between pain and agitation in nursing home residents with dementia; behaviour that could be associated with being in pain, undertreating pain and the different assessment tools that are currently used to assess pain.

Pain and Behaviour

Ahn and Horgas (2013) looked into the relationship between pain and disruptive behaviour of residents in nursing homes. They used secondary analysis from the Minimum data set, (MDS) a federally mandated tool, which guides the regular assessment of nursing home residents in Florida. Therefore although secondary analysis the data set is significant, (n = 56, 577). It was mandatory in these nursing homes to have MDS assessments completed on admission, quarterly and on significant behaviour changes. The data from MDS identified that there was statistical significance between pain and agitated behaviour, including restlessness

and repetitive movements. There was also a statistical significance between pain and aggression which included verbal and physical abuse. The pain was measured from the tool on the MDS, which included observation and verbal pain scales, and they found that a higher pain score was associated with increased agitation.. This can be supported by Miu and Chan's (2014) study which discovered that out of 190 patients reported to have pain, 67 patients displayed verbal aggression and 42 patients displayed physical aggression. They state that due to direct observation of the participants recall bias was kept to a minimum improving the validity of the results. However they did not use a specific tool to measure agitation, unlike Ahn and Horgas (2013) who used the Cohen-Mansfield Agitation Inventory scale(CMAI).. Both Ahn and Horgas (2013) and Miu and Chan (2014), however, recognise that other factors could contribute to disruptive behaviours. This needs to be considered when assessing patients to ensure a correct diagnosis is carried out.

Habiger et al (2016) used secondary analysis of a clustered randomised control trial to investigate a relationship between pain, psychosis and agitation in people with dementia. There was an intervention group who were given individual pain treatment according to a stepwise protocol for treating pain and the control group received treatment as usual. The sample was clustered into three groups, those who were agitated, have psychosis and those with low mood. In the sub group of those with agitation it was identified that overall there was a decrease in agitated behaviour when the residents were given the treatment of pain relief, reinforcing the view that pain increase agitation. They also discovered that there was a decrease in aberrant motor behaviours (includes wandering which was identified as a sign for agitation) within the treatment group, thus suggesting a link between wandering and pain. This is contradicted by Ahn and Horgas (2013) and Miu and Chan (2014) who found no statistical significance between pain and wandering.

Three of the papers (Miu and Chan 2014; Chen et al 2014; Husebo et al 2014) looked at whether pain was associated with depression and agitation, and discovered an association between pain agitation and depression. Husebo et al (2014) considered if pain treatment affected mood in patients with dementia. They discovered that depression was significantly reduced in the treatment group compared to the control group and after eight weeks there was a difference in irritability between the two groups in favour of pain treatment. This can be supported by Miu and Chan (2014) who found that 15% of the patients who had pain also had the presence of depression compared to 8.4% of the patients without pain. Furthermore Chen et al (2014) found a direct association between depression and agitation, and pain was identified to affect agitation via depression. This suggests that pain, depression and agitation could be connected and this would need to be considered when assessing patients, also that further research needs to be undertaken to see the links between depression and pain and agitation.

Undertreating pain.

Ahn et al (2015) specifically looked into the difference between self-reporters of pain and uncommunicative residents and their association with aggression. Self-reporters were assessed using a numerical rating scale or a verbal descriptor scale whilst a MDS-pain behaviour scale was used for uncommunicative residents. They discovered that 89.6% of self-reporters have pain medication compared to 45.6% uncommunicative residents. It needs to be questioned why this big difference occurred. This can be supported by Miu and Chan (2014) who also discovered that nearly twice as many uncommunicative patients were in pain compared to those who could verbally communicate their pain.

In relation to the association between pain and aggression Ahn et al (2015) found that verbal aggression occurred in 4.3% of self-reporters compared to 5.9% of uncommunicative residents and 1.9% of self-reporters displayed physical aggression compared to 7.6% of uncommunicative residents. Therefore those who could express their pain were less agitated than those who could not express their pain. However in this study Ahn et al (2015) noted that a limitation for this study was that compared to previous studies there was a lower percentage of reported aggressive behaviours. They felt that this could be due to a well-managed nursing home or an underreporting of aggression. It does however identify a big difference in physical aggression between the two groups suggesting that pain is undertreated in uncommunicative residents, which could contribute to aggressive behaviour. Miu and Chan (2014) in their observational study identified, however, that the amount of analgesia prescribed was low for all residents. Whilst 61.5% (N = 309) were assessed to have pain only 31% (N = 95) of these residents received analgesia. They also discovered that 54% of the total sample displayed verbal or physical aggression, this could link to the pain they were experiencing. This emphasises the importance of pain assessments and management for residents with dementia to reduce their agitation.

Assessment tools

The use of dementia specific tools to assess agitation and pain can support the reliability and validity of the research. Four of the papers (Husebo et al 2014, Habiger et al 2016, Miu and Chan 2014 and Chen et al 2015) used validated dementia specific pain assessment tools. The use of validated dementia specific pain assessment tools such as those identified in these studies incorporate observation skills of signs of pain. The pain assessment obtained by Ahn and Horgas (2013) and Ahn et al (2015) was from the generic MDS assessments. However, this tool incorporated aspects of observations for signs of distress, including wandering.

The majority of papers identified a behaviour scale alongside the pain tool to help identify a relationship between pain and behaviour. Ahn and Horgas (2013) and Ahn et al (2015) took their data from the MDS where various aspects of agitation are assessed, including verbal aggression, physical aggression, socially inappropriate, resisting care, restlessness and repetitive physical movement. Chen et al (2014), Husebo et al (2014) and Habiger et al (2016) used the validated Cohen-Mansfield Agitation Inventory (CMAI) that contains observations of 29 agitated behaviours over a week. Miu and Chan (2014) however did not use a tool for behaviour, however observations identified whether behaviours such as, verbal disruption, physical aggression and wandering were present or not. Chen (2014) also undertook observation but measured these against the CMAI, whereas the other four papers undertook a secondary analysis which reduces the trustworthiness of the data collected.

Discussion

The review has highlighted that pain can impact upon behavioural changes in people with dementia. In contrast to this review an earlier literature review by Husebo et al (2011) found that there was no reduction in agitation following pain management. There is however limited direct observational research that investigates the links between pain and agitation. A variety of influencing factors were highlighted in this review that suggested agitation which included wandering also the impact of pain and depression. Ahn and Horgas (2013) found that those with more severe pain were less likely to wander and Husebo et al (2014) noted that those in pain were more likely to experience depression. This highlights the complexity of understanding the distressed behaviour of those with dementia. The use of validated pain assessment tools can identify when a person is in pain and an improvement in these scores following pain management would reduce distress, and could improve mobility and a person's mood.

Furthermore supporting patients who are distressed can impact upon the well-being of staff who can feel inadequate in meeting the needs of residents. Research exploring the emotional cost on staff struggling to provide comfort to residents would be helpful.

It has been identified within this review that there continues to be inadequate pain medication administered to residents in nursing homes, as previously revealed by Achterberg et al (2007) and Elseviers et al (2010). . Won et al (2003) also found that only 24% of 10,476 residents with persistent pain received analgesics. Husebo et

al's (2011) literature review suggested that this could be due to nurses believing that patients should be given analgesia 'when required' rather than scheduled doses. They found this proves to be difficult when dealing with patients that cannot communicate their needs. This was reinforced by Ahn et al (2015) and Miu and Chan (2013) who found that pain and aggressive symptoms varied depending on an individual's ability to communicate, disproportionately affecting those who could not articulate their degree of pain.. The implication for practice is that there is a significant difference between administered analgesia between uncommunicative residents and self-reporters. This could mean that many residents that cannot communicate have undiagnosed pain, which could present as agitated behaviour. Future research would need to be conducted on why this occurs such as, difficulties in assessing pain.

There appears to be link between pain and agitation, yet in the studies that used secondary analyses (Ahn et al 2015; Ahn and Horgas 2013; Habiger et al 2016, and Husebo et al 2014) the reliability of the data collected is questionable. No assessment can be made of the knowledge of those completing the assessment. According to Hughes and Lloyd-Williams (2010) incorrectly assessing pain could lead to an under or over diagnosis of pain. They state that pain related behaviours could be attributed to a person's dementia or behaviours related to boredom or loneliness could be seen as pain related, both resulting in misdiagnosis. The research identified that primary caregivers are at the forefront of pain assessments with the use of pain assessment tools. It needs to be questioned whether the primary caregivers are competent to effectively assess pain in people with dementia. Burns and McIlpatrick (2015) literature review identified that caregivers find it difficult to differentiate between behavioural change due to pain or other problems, such as, delirium. Cohen-Mansfield et al(2012) in an earlier study also found that pain is under recognised which results in an over prescribing of anti-psychotic medication and an under prescribing of analgesia. The implication for practice is that incorrect assessments of resident's behaviour could overlook pain as a cause of changes in behaviour and result in the administration of potentially harmful medication that increases agitation. Further research into the experience of pain from the patients experience and the management of pain from a carer's perspective is needed. The use of validated tools to assess pain and behaviour will improve the confidence in data collected. An increased understanding of pain for people with dementia will hopefully improve pain management and ultimately reduce their distress and agitation.

Limitations of this review

All the research papers are cross sectional which prevents a cause and effect relationship from being identified. It can only be suggested that there is an association between pain and agitation. Sedgewick (2014) suggests that it is difficult to determine a temporal association between a risk factor and an outcome because

the data was collected at a single point in time. Another limitation of this review is that the majority of the selected research papers were secondary analyses. This is due to a limited amount original research identified during the search process which specifically investigated pain and agitation. According to Boslaugh (2007) secondary analyses enable large sample sizes due to using pre-existing data. She states however, that a disadvantage is that the analyst cannot be certain that the data is trustworthy because they were not present when it originally took place. Further research is needed to give support to this review. Longitudinal studies would identify if analgesia reduces agitation over time or randomised placebo controlled trials could investigate the effectiveness of pain treatment on agitation.

Conclusion

This review was conducted to identify if there were links between pain and agitation in nursing home residents with dementia. Drawing upon the findings from the research papers there appears to be an association between pain and agitation. More empirical research that investigates the cause and effect relationship between pain and agitation needs to be undertaken, using validated tools to assess pain and agitation. Also the impact or a broad range of pain management strategies including analgesia needs further investigation.

Verbal or physical aggression was identified to be more prevalent in uncommunicative residents. It was also highlighted that uncommunicative patients received less prescribed analgesia than patients that could self-report. It needs to be questioned whether these are related. Supporting literature within the discussion section suggests that this could be due to ineffective assessments of pain, whether it is from difficulties in recognising pain or the effectiveness of the assessment tool itself. More research is needed on the current tools to identify effectiveness of assessing pain in uncommunicative residents. However, pain assessment tools on their own are merely a tool and knowing the individual patient and good observational skills are essential. Person centred care will help identify what factors exacerbate or relieve pain so nurses can work towards providing comfort and effective pain relief..

Key Points

- 30-60% of nursing home residents that have late stage dementia suffer from daily pain
- Underdetected pain can impact upon behavioural changes in people with dementia living in nursing homes.
- Residents who have difficulty verbalising their needs do not receive as much analgesia as those that can.
- Accurately assessing pain would be the first step in discovering whether pain causes agitation.

CPD reflective questions

- Are there residents with dementia in your place of work who appear distressed and agitated who might be in pain?
- What tools are available to assess the pain of those who cannot verbally express themselves?
- Consider what other factors might cause distressed behaviour in those residents who have dementia.

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