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Review

Interventions targeting pain or behaviour in dementia: A systematic review

Marjoleine J.C. Pieper^{a,b}, Annelore H. van Dalen-Kok^c, Anneke L. Francke^{a,d},
Jenny T. van der Steen^a, Erik J.A. Scherder^e, Bettina S. Husebø^f, Wilco P. Achterberg^{a,c,*}

^a EMGO⁺ Institute for Health and Care Research, van der Boechorststraat 7, 1081 BT Amsterdam, The Netherlands

^b Department of General Practice & Elderly Care Medicine, VU University Medical Center Amsterdam, van der Boechorststraat 7, 1081 BT Amsterdam, The Netherlands

^c Department of Public Health and Primary Care, Leiden University Medical Center, Post zone V0-P, PO Box 9600, 2300 RC Leiden, The Netherlands

^d Netherlands Institute for Health Services Research (NIVEL), PO Box 1568, 3500 BN Utrecht, The Netherlands

^e Department of Clinical Neuropsychology, VU University Amsterdam, van der Boechorststraat 1, 1081 BT Amsterdam, The Netherlands

^f Department of Public Health and Primary Health Care, University of Bergen, Bergen, Norway

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ABSTRACT

Background: Both pain and challenging behaviour are highly prevalent in dementia, and multiple studies show that some of these behaviours may be correlated. Pain, especially in non-communicative patients, can cause challenging behaviour, and treatment of pain therefore may have an effect on behaviour. This review aims to provide a comprehensive overview of the current state of evidence regarding the effectiveness of interventions targeting pain on the outcome behaviour, and interventions targeting behaviour on pain, in dementia.

Method: PubMed (MEDLINE), EMBASE, COCHRANE, CINAHL, PsychINFO and Web of Science were searched systematically. Studies were included if they focused on an intervention targeting a reduction in the person's distress, pain, and/or behaviour, and included adults with a main diagnosis of dementia.

Results: Of a total of 893 potentially relevant publications that were identified, 16 publications met the inclusion criteria and were eligible for further analysis; 6 studies focused on a pain intervention targeting behaviour, 1 study focused on a behavioural intervention targeting pain, and 9 studies focused on an intervention targeting both pain and behaviour.

Conclusion: Available evidence suggests that (pain) interventions targeting behaviour, and (behavioural) interventions targeting pain are effective in reducing pain and behavioural symptoms in dementia.

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* Corresponding author at: Department of Public Health and Primary Care, Leiden University Medical Center, Post zone V0-P, PO Box 9600, 2300 RC Leiden, The Netherlands. Tel.: +31 0 71 526 8412.

E-mail addresses: m.pieper@vumc.nl (M.J.C. Pieper), a.h.van.dalen@lumc.nl (A.H. van Dalen-Kok), a.francke@nivel.nl (A.L. Francke), j.vandersteen@vumc.nl (J.T. van der Steen), eja.scherder@vu.nl (E.J.A. Scherder), bettina.husebo@isf.uib.no (B.S. Husebø), w.p.achterberg@lumc.nl (W.P. Achterberg).

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1. Background

Dementia is a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical and neuropsychological functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement (WHO, 1992).

Next to cognitive dysfunction, neuropsychiatric symptoms are prominent in most patients during the disease. These symptoms include delusions, hallucinations, agitation/aggression, dysphoria/depression, anxiety, euphoria/elation, apathy/indifference, disinhibition, irritability/lability, aberrant motor behaviour, night-time disturbances and appetite/eating disturbances. In patients with dementia up to 80–85% have one or more of these (clinically relevant) neuropsychiatric symptoms (Kverno et al., 2008; Norton et al., 2010; Zuidema et al., 2007). Often, these symptoms are also referred to as challenging behaviour (Kverno et al., 2008; Norton et al., 2010; Zuidema et al., 2007).

Pain is also highly prevalent in patients suffering from dementia. Epidemiologic studies have shown a very high prevalence of persistent pain, often exceeding 50% of community-dwelling older persons and up to 80% of nursing home residents (Achterberg et al., 2010; Boerlage et al., 2008; Gibson, 2007; Sawyer et al., 2007; Takai et al., 2010; Zwakhalen et al., 2009). Behaviours, such as verbalizations/vocalizations (e.g. sighing, moaning, calling out, verbal abuse), noisy breathing, facial expressions (e.g. grimacing, frowning), restless or strained body expressions (e.g. rigid, tense, guarding, fidgeting, increased pacing/rocking), agitation/aggressiveness and resistance to care, are frequently the most prominent, or even the only feature of pain (AGS, 1998, 2002; Geda and Rummans, 1999; Kovach et al., 2001; McMinn and Draper, 2005). These behaviours are, however, often not recognized as a symptom of pain, but frequently interpreted as a symptom of the dementia. As the prevalence of dementia will rise exponentially within the next few years, behaviours like pain and neuropsychiatric symptoms, will consequently rise exponentially as well. To date, these behaviours already have a tremendous impact on the quality of life in patients with dementia, on caregiver-burden and earlier institutionalizations, and are furthermore associated with a rapid progression of cognitive & functional decline (Echavarrri et al., 2012; Finkel, 2001). So, this impact will only increase, and will affect patients, caregivers and society.

In literature, it has been shown consistently that patients with dementia are undertreated for pain (Achterberg et al., 2007; Frampton, 2003; Nygaard and Jarland, 2005; Scherder et al., 2005; Tait and Chibnall, 2008). In addition, research also indicates that pharmacological interventions (analgesic medication), as well as non-pharmacological comfort measures for pain and behavioural disturbances are underutilized (Feldt et al., 1998; Herr, 2002; Horgas, 2003). The main explanation for this under-detection and

under-treatment of pain is, that people with dementia report pain less often, less spontaneously, and at a lower intensity than those without a cognitive impairment do (Zwakhalen et al., 2006). Generally, the more severe the dementia, the less capable patients become of being able to verbally express their pain or discomfort (McAuliffe et al., 2012). Because they become less capable of verbally expressing their pain or discomfort, important information becomes inaccessible for caregivers. Before specific therapies can be considered, a comprehensive assessment is therefore essential. A thorough clinical evaluation is likely to highlight pharmacological and non-pharmacological opportunities for treatment of both the behavioural symptoms and pain (Ballard et al., 2011). A recent study of Cohen-Mansfield showed that this 'recognition of pain' is one of the barriers for caregivers (Cohen-Mansfield et al., 2012). And because of this barrier, people with dementia are more likely to receive psychotropic medications rather than adequate pain treatment, despite all the adverse effects of these psychotropic drugs (e.g. drowsiness, depressed mood and falls) (Ballard et al., 2009; Briesacher et al., 2005).

Pharmacological interventions traditionally have had an important role in influencing challenging behaviour, but as mentioned above they have serious side effects and a potential harmful impact on the quality of life (Ballard and Margallo-Lana, 2004). Relatively recent research demonstrated the efficacy of pain treatment, in order to reduce behavioural symptoms in dementia (Chibnall et al., 2005; Husebo et al., 2011b). An increasing amount of evidence has shown that psychosocial- and behavioural interventions are effective in reducing challenging behaviours (Ayalon et al., 2006; Brodaty and Arasartnam, 2012; Cooper et al., 2012; Kverno et al., 2009; Livingston et al., 2005; Vernooij-Dassen et al., 2010), but the connection with pain – as a cause of underlying pain or distress – has been made by only a few studies, and very little is known about the influence of these behavioural interventions on pain. How pain and challenging behaviour co-occur is still unclear, but multiple studies have shown they are strongly correlated (Husebo et al., 2011a; Tosato et al., 2012). Although research on the 'recognition of pain in dementia' is receiving more attention, it is still unclear which interventions are effective in reducing pain and behavioural symptoms in dementia at the same time.

Therefore, this review aims to provide a comprehensive overview of the current state of evidence regarding the effectiveness of interventions targeting pain on the outcome behaviour, and interventions targeting behaviour on pain in dementia.

2. Methods

2.1. Search

A systematic search of the literature was conducted in March 2012. Databases searched included PubMed (MEDLINE), EMBASE,

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