

ORIGINAL PAPER**Pain among Persons with Dementia: The Family Caregiver's View Point****Päivi Kankkunen, RN, PhD**

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e-mail paivi.kankkunen@uef.fi**Abstract****Background:** Dementia and pain are common among the elderly. Many of persons with dementia live at home and are cared by their family caregivers. Pain in persons with dementia can be challenging for family caregivers because the patients are often unable to express their pain verbally. Instead, they might express the pain with disruptive behavioral changes. These changes may cause burden for the caregivers. Earlier research has focused on pain assessment and management of persons with dementia living in institutionalized care. Instead, we were interested in the view point of family caregivers.**Aims:** To describe pain assessment and management among persons with dementia at home care from the view point of family caregivers.**Methodology:** Literature review was used to collect the data and inductive content analysis was used in the analysis.**Results:** Five scientific articles were found focusing on the view point of caregivers of persons with dementia. The scope of the studies was mostly on validation of pain rating scales and comparison of pain ratings by the patient and family caregiver. No studies were found on pain management at home. However, the family members felt distressed because of fears that the patient had pain. No studies were found of family caregiver's experiences of pain assessment and management among persons with dementia.**Conclusions:** Fairly little is known how family caregivers assess and manage pain among persons with dementia at home. Empirical studies are needed to better understand pain management among persons with dementia from the view point of family caregivers.**Key words:** dementia, pain, chronic pain, family caregiver, family care**Background**

The purpose of this study was to describe pain assessment and management among persons with dementia at home care from the view point of family caregivers. This review focuses on synthesize the current evidence on pain assessment and management among home-dwelling persons with dementia.

Rapid increases of number of and proportion of older people have profound impact to health care

(Prince et al., 2013, Wimo et al., 2013). Aging increases the prevalence of dementia. Dementia is a clinical syndrome caused by neurodegeneration and characterized by deterioration of cognitive ability and capacity for independent living. The most common diseases leading to dementia are Alzheimer's disease, vascular dementia, Lewy body and frontotemporal dementia (Prince et al., 2013). Alzheimer's disease (AD) is the most common neurodegenerative disease leading to cognitive

impairment and eventually dementia. AD is characterized by progressive cognitive decline, loss of daily functions and neuropsychiatric symptoms (Hallikainen et al., 2013). Age standardized prevalence of dementia for people aged ≥ 65 years vary 5%-7% in most world regions (Matthews et al., 2013, Prince et al., 2013).

The current tendency is to support community-dwelling care as long as possible and delay institutionalization. Family care will become more common in health care systems for persons with dementia. Family caregivers provide the majority of home care and continue care up to the advanced stage of dementia. Thus, family caregivers face challenges managing symptoms of dementia, care of physical symptoms, responsibility of medication as well as constant supervising and monitoring of the person with dementia (Välimäki et al., 2012).

Aging seems to increase pain. Pain is defined as "an unpleasant sensory or emotional experience associated with actual or potential tissue damage or described in terms of such damage" (Merskey & Bogduk, 1994). The population based health survey (Kuopio 75+ study) analysed the prevalence of daily pain and analgesics used among home-dwelling people aged 75 years and older with and without dementia. This study showed that the prevalence of daily pain increased with age in both persons with or without dementia. However, dementia was related to a lower prevalence of reported pain and analgesic use. (Mäntyselkä et al., 2004.) The most common sites of pain in the elderly are the back, leg/knee/hip or "other" joints (Abdulla et al., 2013).

Assessment of pain provides basis for effective pain management. However, differentiating pain from other neuropsychiatric disturbances in memory disorder patients, such as agitation, anxiety, apathy, irritability may be challenging for family caregivers. Persons with severe dementia are usually not able to express their pain verbally, but instead they express it e.g. facial grimacing, moaning and groaning, aggression, restless body movements, anxiety and resisting care (Kovach et al., 2006, Ballard & Bannister, 2010).

Several tools exist to be used in assessment of pain in elderly with dementia. In the early state of dementia some patients may be able to use simple pain rating scales, like Faces Pain Scale. However, even slight cognitive impairment was found to induce difficulties in completing FPS scale (Pesonen, 2011). For example, PAINAD (Pain Assessment in Advanced Dementia) seemed to be valid tool to assess pain while related to self-reported and proxy-reported, by scores on DOLOPLUS2 and while comparing the scores in painful and supposedly less painful conditions. Cut-off point for pain treatment was defined as 2 out of 10 PAINAD scores. (Zwakhalen, van der Steen & Najim, 2012).

Additionally, the Non-Communicative Patient's Pain Assessment Instrument (NOPPAIN) is found to be valid in identifying pain behaviors in patients with dementia (Snow et al. 2004). However, the tools are mainly developed for professional use in health care. For example self-reporting tools cannot be used with patients having severe dementia. Additionally, the tools have been validated mainly in institutional care and fairly little is known how family caregivers assess the pain at home.

Pain can be managed using analgesics and non-pharmacological methods. WHO (1986) suggests ladders for use of analgesics. Pain can be treated using simple analgesics (i.e. paracetamol and non-steroidal anti-inflammatory drugs, NSAIDs), weak opioids, strong opioids and adjuvants (drugs which were not originally for pain but rather for other conditions but have been found to be effective in managing pain) (see also Guidance on the management of pain in older people 2013).

All analgesics may have adverse effects but used at the right dosage e.g. opioids may cause predictable and preventable adverse effects (Gianni et al., 2009). In addition, non-pharmacological methods can be applied to manage pain. These methods include e.g. physical methods, such as massage, pressure application, cold and hot compresses and repositioning, as well as psychological methods such as distraction. (e.g. Titler et al., 2003, Mehta et al., 2010, Guidance on the management of pain in older people 2013).

Existing evidence (e.g. Husebo et al., 2008) suggests that pain is underdetected and undertreated among cognitively impaired people living in institutions. There are several dementia-related factors to unsuccessful pain assessment and management of persons with dementia. The reporting habits of persons with dementia may lead to misunderstandings and the acceptance of these reports by care staff (Cook, Niven & Downs, 1994.) There may be insufficient knowledge of pain manifestation among people with dementia. Health professional may fail to recognize the pain, interpret the symptoms as emotional distress (McAuliffe et al., 2008). Moreover, inadequate use of pain assessment tools for measuring pain (Schofield et al., 2006, McAuliffe et al., 2008, McAuliffe, Brown & Fetherstonhaug, 2012).

The current literature has focused on pain management in nursing homes (e.g. Barry et al., 2012), in hospices (Miller et al., 2008), in residential care (Abdullah et al., 2013), recognizing of pain (Black et al., 2006), evaluation of suitable pain assessment methods (Buffum & Haberfelde, 2007) and evaluation of the usefulness of pain scales within persons with dementia (Edvardsson, Katz & Nay, 2008) as well as the professional staffs attitude towards pain management (Barry et al., 2012). Meanwhile, the family caregivers' knowledge of pain, appropriate means to assess pain and ability to relief the pain in home care settings are not yet studied. The assessment and management of pain in home care by family caregivers pose many challenges.

Yet, the role of families has been highlighted in care of persons with dementia. The majority of persons with AD are living in their own homes, at least at the mild and the moderate stages of AD, with the care of a family caregiver. The consequences of caregiving are diverse and complex (Brodaty & Donkin, 2009). Caring for relatives with dementia is consistently associated with noticeably higher stress levels and a high possibility for psychological and physical health problems (Pinquart & Sörensen, 2003), which potentially increase the use of social and health care services leading to an even higher societal burden of dementia (Välimäki et al., 2012). Earlier studies have shown that family caregivers of dementia patients have three dimensions of

strain: role, personal and emotional. Patient's problem behaviors predicted all of the strain dimensions. (Diwan, Hougham & Sachs, 2004.) In addition, carers of persons with dementia have reported varying degrees of care burden, mainly poorer health status with physical functioning and pain compared to general population (Homer et al., 2012).

Research questions:

- 1) How do family caregivers assess pain among persons with dementia?
- 2) How do family caregivers manage pain among persons with dementia?
- 3) What kind of experiences do family caregivers have of pain management among persons with dementia?

Methodology

Data were searched from data basis Cinahl, PubMed, Medic, Cochrane and Scopus.

Key words "pain", "dementia or cognitive impairment", "family care or family caregiver", "home care" were used alone and combined with each other. The same key words were used translated to Finnish in data base Medic. The search was limited between years 2000 and 2013. Data search strategy is presented in table 1.

Exclusion criteria were: the article was not a study report, the report was not published in English, Finnish or Swedish, the study was not focused on family caregivers of persons with dementia or the study was not conducted in an out-patient setting. In addition, studies focusing on other symptoms than pain, acute pain or caregiver's pain were excluded from the analysis.

First, the titles of the articles were examined by two researchers independently, and articles not fulfilling the inclusion criteria were excluded. After that the second selection was conducted based on the abstracts of the articles. After reading the abstracts the final decision of selection of the articles for the analysis was done in agreement with two researchers. Table 1 describes the number of hits, abstracts read and articles included into the analysis.

The articles were analyzed by the means of inductive content analysis (Burns & Grove, 2009, Kankkunen & Vehviläinen-Julkunen, 2013).

Table 1. Description of the literature search.

Data base	Search terms	Hits (N)	Abstracts (n)	Included in analyses (n)
Cinahl	pain + dementia +patient + home care	33	11	3**
Cinahl	pain + dementia patients + family care	26	11	4**
PubMed	chronic pain + CI + home	21	21	0
PubMed	chronic pain + CI + family	14	14	0
Medic	kipu (pain) + dementia	10	10	0
Medic	kipu (pain) + muistisairaus (CI*)	6	6	0
Cochrane	pain + CI + family care	2	2	0
Cochrane	pain + CI + home	1	1	0
Scopus***	pain + dementia +patient + home care	52 6	3 (1 **)	
Scopus***	pain + dementia patients + family care	24	23	0
Scopus***	pain + CI + family care	14	14	0
Scopus***	pain + CI + home	63	4	0

*CI = cognitive impairment

** same hits

***nursing

Results

The five studies included in the review are presented in Table 2. The results present the current state of assessing and managing pain of home-dwelling persons with dementia by family

caregivers. Even if the concept cognitive impairment was used as synonym to dementia in previous studies, in description of results we are using concept dementia to cover all memory diseases.

Table 2. Analysis of the studies.

Author	Purpose of the study	Sample and methods	Main findings
Boyer et al. 2004, France	To examine agreement between patients' and their proxy reports on health status in patients with CI	99 patients and proxies. Nottingham Health Profile. Statistical analysis.	Patient/family proxy concordance was moderate to good for e.g. pain
Givens et al. 2011, USA	To describe family members' exposure to distressing symptoms. Questionnaires Statistical analysis	Nursing home residents	19 % of family members felt distressed because of fears that the resident had pain.
Krulewitch et al. 2000, USA	To compare self-reporting of pain by CI older adults and their caregivers.	156 CI adults and their caregivers. Three pain assessment tools. Statistical analysis.	One third of CI adults were unable to use any tool. Mean scores of adults with CI and caregivers did not differ significantly.
Murray et al. 2012, USA	To identify the most bothersome experiences self and caregiver report.	150 community-dwelling patient –caregiver dyads.	Pain was the most frequently reported physical symptom both patients and caregivers.
Shega et al. 2004, USA	To understand pain experience of persons with dementia	150 patient-family carer dyads. Questionnaires Statistical analysis	59% of dyads were congruent with respect to their reports of pain. Congruence was higher with male patients, MMSE over 10, lower levels patients' agitation.

Analysis of the literature showed that research in pain assessment has focused mainly on comparison of pain ratings among persons with dementia and their family caregivers. No study reports were found about pain management at home. One report was found about caregiver's experience of pain in the dementia patient.

Assessment of pain in persons with dementia described by family caregivers

According to the findings family caregivers assess pain in concordance with persons with dementia. The pain ratings by the elderly with dementia (mean MMSE score 15.7) and their family members showed that the reports were fairly similar while assessing the level of pain experienced by the patients. However, one third of the patients with dementia were unable to complete any of the three pain assessment tools (Nonverbal Visual Analog Scale, The Faces Pain Scale, the Philadelphia Pain Intensity Scale). Additionally, the number of tools completed by the adults with dementia decreased with increased cognitive deterioration (Krulwich et al., 2000).

Concordance of assessments of health status by persons with mild to moderate dementia and their proxies was moderate to good for five out of six dimension, including pain (Boyer et al. 2004). Both community-dwelling persons with dementia and their caregivers reported pain to be the most frequently reported physical symptom (Murray et al., 2012).

While comparing pain assessment among persons with dementia and their caregivers, it was found that more than half (59 %) of the dyads agreed on the presence or absence of pain. Caregivers used to report more pain (52 %) than the persons with dementia (32 %). Dyadic congruence was higher while the patient was male, MMSE was more than 10 and the level of patients' agitation was low. Additionally, dyadic congruence was higher when the caregivers were female, had low levels of caregiver strain and low levels of depression. (Shega et al., 2004.)

Management of pain in persons with dementia described by family caregivers

The existing literature on pain management with persons with dementia is substantial. However, we did not find studies conducted in family care settings which evaluate what kind of methods the

family caregivers use to manage pain in persons with dementia.

Experiences of family caregivers of pain management among persons with dementia

We found no studies focusing on the experiences of family caregivers of pain management among persons with dementia in family care context. However, pain in nursing home residents with advanced dementia was one the most common reason for distressing symptoms among their family members. A sense of helplessness was highest when the resident was observed to be in pain. (Givens et al., 2011).

Discussion

Ethical considerations

The research topic is important and actual. Persons with dementia can be defined as vulnerable persons because they may not be able to express and manage their pain by themselves. Literature searches and the findings were described openly.

Study limitations

The results of this literature cannot be generalized because of small number of studies found for the analysis. On the other hand, literature search was conducted from reliable scientific data basis. The analysis showed need for further research especially about pain management and the experiences of it described by family caregivers.

Discussion of the findings

According to this literature analysis, research focusing on assessment and management of pain in persons with dementia from the view point of family caregivers has been very limited. Most of studies (Boyer et al., 2004, Krulwich et al., 2000, Shega et al., 2004) were conducted to compare pain ratings given by patients with dementia and family caregivers. However, very little is known how family caregivers assess the pain if they do not have any tool to be utilized at home.

Pain was the most frequently reported physical symptom for patients and caregivers (Murray et al., 2012). Additionally, fear of pain was one reason for distress among family members having their relative living at nursing homes (Givens et al., 2011). It is possible that family

members consider themselves as experts to identify pain in persons with dementia and may not trust that the pain can be identified and managed in the nursing home.

However, with the increased need to enable family care as long as possible provides a demand for further research in this area. Number of patients with dementia is increasing while the population is aging. Many diseases become common with the increased age and many of them cause pain. Therefore, more research is needed about pain assessment and management at family care. With this information, guidance, counseling and support of patients and their caregivers can be further developed.

References

- Abdulla A, Adams N, Bone M, Elliott A, Gaffin J, Jones D, Knaggs R, Martin D, Sampson L & Schofield P. (2013). Guidance of the management of pain in older people. *Age & Ageing* 42: Suppl 1:i1-57.
- Ballard C & Bannister C (2010). Criteria for the Diagnosis of Dementia. In: Ames D, Burns A & O'Brien J. *Dementia*, 4th Edition, CRC Press: 39.
- Barry HE, Parsons C, Passmore A & Hughes CM (2012). An exploration of nursing home managers' knowledge of and attitudes towards the management of pain in residents with dementia. *International Journal of Geriatric Psychiatry* 27(12):1258-66.
- Black B, Finucane T, Baker A, Loreck D, Blass D, Fogarty L, Phillips H, Hovanec L, Steele C & Rabins PV (2006). Health problems and correlates of pain in nursing home residents with advanced dementia. *Alzheimer Disease and Associated Disorders* 20(4):283-90.
- *Boyer F, Novella J, Moorone I, Jolly D & Blanchard F (2004). Agreement between dementia patient report and proxy reports using the Nottingham health Profile. *International Journal of Geriatric Psychiatry* 19(11): 1026 – 1034.
- Brodsky H & Donkin M (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience* 11(2): 217-228.
- Buffum M & Haberfelde M (2007). Cognitive impairment and pain management: Review of issues and challenges. *Journal of Rehabilitation Research & Development* 44 (2): 315-330.
- Burns N & Grove S (2009). *The practice of nursing research. Appraisal, synthesis and generation of evidence.* Saunders, Missouri, USA.
- Cook A, Niven C & Downs MG (1999). *Assessing the pain of people with cognitive impairment.* International Journal of Geriatric Psychiatry 14(6):421-425.
- Diwan S, Hougham G & Sachs G (2004). Assessing families in palliative care: A pilot study of the checklist of family relational abilities. *Journal of Palliative Medicine* 7(6): 797 – 807.
- Doherty A, Owens A, Asadi-Lari M, Petchey R, Williams J & Carter Y (2008). Knowledge and information needs of informal caregivers in palliative care: a qualitative systematic review. *Palliative Medicine* 22: 153-171.
- Edvardsson D, Katz B & Nay R (2008). The aged care pain chart: An innovative approach to assessing, managing and documenting pain in older people. *Australasian Journal of Aging* 27 (2): 93-96.
- Fulton A, Rhodes-Kropf J, Corcoran A, Chau D & Castillo E (2011). Palliative care for patients with dementia in long-term care. *Clinics in Geriatric Medicine* 27(2): 153 – 170.
- Gianni W, Ceci M, Bustacchini S, Corsonello A, Abbatecola A, Brancati A, Assisi A, Scuteri A, Cipriani L & Lattanzio F (2009). Opioids to the treatment of chronic non-cancer pain in older people. *Drugs & Aging* 26, Suppl1: 63-73.
- *Givens J, Prigerson H, Jones R & Mitchell S (2011). Mental health and exposure to patient distress among families of nursing home residents with advanced dementia. *Journal of Pain and Symptom Management* 42(2): 183 – 191.
- Guidance on the management of pain in older people (2013). *Age and Ageing* 42: I1 – I57. doi: 10.1093/ageing/afs200.
- Hallikainen I, Hänninen T, Fraunberg M, Hongisto K, Välimäki T, Hiltunen A, Karppi P, Sivenius J, Soininen H & Koivisto AM (2013). Progression of Alzheimer's disease during a three-year follow-up study. The CERAD-NB total score: Kuopio ALSOVA study. *International Psychogeriatrics* 25(8): 1335-1344.
- Homer B, Jiwa M, Cuesta-Briand B, Fyfe K & Osborne A (2012). Proactive primary care of carers of people with cognitive impairment: a feasibility study. *Quality in Primary Care* 20(6): 415-420.
- Husebo B, Strand L, BorgeHusebo S, Aarsland D & Ljunggren A (2008). Who suffers most? Dementia and pain nursing home patients: a cross-sectional study. *Journal of the American Medical Directors Association* 9(6): 427 – 433.
- Kankkunen P. & Vehviläinen-Julkunen K. (2013). *Tutkimus hoitotieteessä (Research in nursing science).* WSOYpro, Helsinki, Finland. 3rd edition.
- Kovach C, Noonan P, Schildt A, Reynolds S & Wells T (2006). *Dementia intervention an approach to*

- treating unmet needs. *Journal of Gerontological Nursing* 32(4): 17-27.
- *Krulwich H, London M, Skakel V, Lundstedt G, Thomason H & Brummel-Smith K (2000). Assessment of pain in cognitively impaired older adults: a comparison of pain assessment tools and their use by nonprofessional caregivers. *Journal of the American Geriatrics Society* 48(12): 1607 – 1611.
- Matthews F, Arthur A., Barnes L, Bond J, Jagger C, Robinson L & Brayne C. (2013). A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: Results of the cognitive function and ageing study I and II. *The Lancet*, in press.
- McAuliffe L, Nay R, O'Donnell M, Fetherstonhaugh D (2009). Pain assessment in older people with dementia: Literature review. *Journal of Advanced Nursing* 65(1):2-10.
- McAuliffe L, Brown D, Fetherstonhaugh D (2012). Pain and dementia: An overview of the literature. *International Journal of Older People Nursing* 7(3):219-26.
- Mehta S, Siegler E, Henderson C & Reid M (2010). Acute Pain Management in Hospitalized Patients with Cognitive Impairment: A Study of Provider Practices and Treatment Outcomes. *Pain Medicine* 11: 1516–1524.
- Merskey H & Bogduk N (1994). *Taxonomy of pain terms & definitions*. IASP Press, Seattle, USA.
- Miller S, Kiely D, Teno J, Connor S & Mitchell S (2008). Hospice care for patients with dementia: does volume make a difference? *Journal of Pain and Symptom Management* 35(3): 283 – 291.
- *Murray T, Sachs G, Stocking C & Shega J (2012). The symptoms experience of community-dwelling persons with dementia: Self and caregiver report and comparison with standardized symptoms assessment measures. *American Journal of Geriatric Psychiatry* 20(4): 298-305.
- Mäntyselkä P, Hartikainen S, Louhivuori-Laako K & Sulkava R (2004). Effects of dementia on perceived daily pain in home-dwelling elderly people: a population based study. *Age and Aging* 33: 496-499.
- Pesonen A 2011. Pain measurement and management in elderly patients. Clinical studies in long term hospital care after cardiac surgery. Academic dissertation. Medical faculty of the University of Helsinki. Available at: <https://helda.helsinki.fi/handle/10138/28175?show=full>.
- Pinquart M & Sörensen S (2003). Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: a meta-analysis. *Journals of Gerontology Series B: Psychological Sciences & Social Sciences* 58B(2): P112-28.
- Prince M, Bryce R, Albanese E, Wimo A, Ribeiro W & Ferri C (2013). The global prevalence of dementia: A systematic review and meta-analysis. *Alzheimer's and Dementia*, 9(1): 63-75.
- *Shega J, Hougham G, Stocking C, Cox-Hayley D & Sachs G (2004). Pain community-dwelling persons with dementia: frequency, intensity, and congruence between patient and caregiver report. *Journal of Pain and Symptom Management* 28(6): 585-592.
- Schofield P, Clarke A, Faulkner M, Ryan T, Dunham M & Howarth A (2006). Assessment of pain in older people. where are we now and what needs to be done? *International Journal on Disability and Human Development* [Internet]. 5(1):3-8
- Snow A, Weber J, O'Malley K, Cody M, Back C, Bruera E, Ashton C & Kunik M (2004). NOPPAIN: a nursing assistant-administered pain assessment instrument for use in dementia. *Dementia & Geriatric Cognitive Disorders* 17(3): 240 – 246.
- Titler M, Herr K, Schilling M, Marsh J, Xie X, Ardery G, Clarke W & Everett L (2003). Acute Pain Treatment for Older Adults Hospitalized with Hip Fracture: Current Nursing Practices and Perceived Barriers. *Applied Nursing Research* 16 (4): 211–27.
- Välimäki T (2012). Family caregivers of persons with Alzheimer's disease: Focusing on the Sense of Coherence and adaptation to caregiving. University of Eastern Finland. Dissertations in Health Sciences 116, Kuopio. URL: http://epublications.uef.fi/pub/urn_isbn_978-952-61-0808-7/urn_isbn_978-952-61-0808-7.pdf.
- Välimäki T, Vehviläinen-Julkunen K, Pietilä AM. & Koivisto A (2012). Life orientation in Finnish family caregivers' of persons with Alzheimer's disease: A diary study. *Nursing and Health Sciences* 14(4): 480-487.
- Wimo A, Jönsson L, Bond J, Prince M & Winblad B (2013). The worldwide economic impact of dementia 2010. *Alzheimer's and Dementia* 9(1): 1- 11.
- Zwahlen S, van der Steen J & Najim M (2012). Which score most likely represents pain on the observational PAINAD scale for patients with dementia? *Journal of the American Medical Directors Association* 13(4): 384 – 389.
- *Article included in the analysis