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Pain and its consequences in dementia: Observing the complex relationship between pain, behaviour and ADL in nursing home residents

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CHAPTER 1

General introduction



A 65-year-old man named Hans has Lewy body dementia and Parkinson's disease. He lives on a psychogeriatric ward in a nursing home and suddenly started exhibiting agitated and even (physically) aggressive behaviour towards other residents. Nursing staff described several incidents where he, for example, physically assaulted another male resident by hitting him in the face without any provocation. He was also verbally aggressive towards nursing staff as well as to other residents. This new and unpredictable behaviour often caused interaction problems, leading to more aggressive incidents between him and other residents, and nursing staff. Nursing staff struggled to identify possible causes for the agitated and aggressive behaviour and were not successful in initiating effective interventions to counteract the behaviour. Furthermore, his wife also noticed a significant change in his behaviour and did not recognize her husband. She also noticed a change in his mobility; there were more OFF moments and he was limping with his right foot. It wasn't until his wife shared her concerns about his mobility that the nursing staff started to realize what might be the cause of his behaviour. Could it be pain?

This case illustrates a common situation on psychogeriatric wards in nursing homes. A combination of dementia, challenging behaviour, change in ADL functioning, and the possible presence of pain, all of which combined impact quality of life.

Dementia

Dementia is a major public health issue worldwide. It is associated with mortality and global economic costs. Dementia is not only overwhelming for the people who are diagnosed with the disease, but also for their relatives and caregivers.¹ Dementia is described as a clinical syndrome of a deterioration in memory, thinking, behaviour, and the ability to perform activities of daily living. Furthermore, it is characterized by its progressive nature. The most common cause of dementia is Alzheimer's disease, followed by vascular dementia, dementia with Lewy bodies, and frontotemporal dementia.²

Besides deterioration of cognition, the neuropathological changes of the brain are also responsible for numerous other symptoms, such as neuropsychiatric symptoms (e.g. agitation, hallucinations and restlessness), loss of communicative abilities, and they have an impact on the perception of pain.³

Pain

Ageing is a high risk for developing pain-related conditions, such as osteoporosis, arthrosis, and cardiovascular diseases.^{4,5} Additionally, ageing is also the greatest risk for developing dementia. Therefore, it is to be expected that persons with dementia also experience pain. Previous research indicates that around 60% to 80% of people with dementia regularly experience pain.⁶⁻⁸

In order to understand the relationship between pain and dementia, the concept of pain needs to be addressed. The International Association for the Study of Pain (IASP) described pain in the following definition: "Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage".⁹ However, this definition is difficult to use in persons with dementia because of terms like 'emotional experience'. Research on the emotional responsiveness to pain in persons with dementia is contradictory; both increased and decreased responsiveness were found. Furthermore, neuropathological changes in the brain, such as white matter lesions and atrophy, affect different parts of the brain: hippocampus, somatosensory cortex, and the amygdala, which all have a specific role in the nociception and experience of pain.³ For example, the somatosensory cortex is important in localizing pain, the hippocampus is important in pain memory, and the amygdala is important in the emotional experience of pain.^{3 10 11} One can imagine that, with these changes, the concept of pain in persons with dementia is different. Additionally, pain has several dimensions, i.e., biological, psychological, and social dimensions.¹²⁻¹⁴ These are interconnected and result in a personal experience and expression of pain. Furthermore, the communicative abilities are also affected, which makes it difficult for them to verbalize their pain. All these changes combine to create a complex relationship between pain and dementia, causing various problems, for example with regard to recognizing that a person with dementia is in pain, and subsequently, providing adequate treatment of pain.

Recently, the IASP introduced a new definition of pain: '*an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage*'. They also formulated accompanying notes, such as: pain is always a personal experience that is influenced to varying degrees by biological, psychological, and social factors. Pain and nociception are different phenomena, and verbal description is only one of several behaviours to express pain.¹⁵ Especially the latter is important in the recognition of pain in persons with dementia.

Neuropsychiatric symptoms

Neuropsychiatric symptoms (NPS), or challenging behaviour, such as agitation, aggression, but also depression and apathy, are common in persons with dementia. About 90% experience a form of challenging behaviour during the course of the disease.¹⁶ Moreover, this is one of the most important reasons for institutionalization.¹⁷ Over the years, several theoretical models were created which describe the aetiology of NPS.^{18 19} One of the models is the Unmet Needs Model.²⁰

Unmet needs are individual needs stemming from habits, personality, environmental conditions, and physical/mental state. Examples are hunger, thirst, lack of activities, and untreated pain. The Unmet Needs Model postulates a mismatch between the needs of the persons with dementia and care provided by environment and caregivers.²¹ In dementia, especially the advanced stage, there is a decrease in the ability to meet one's needs, due to loss of communicative skills, and the ability to provide for oneself. Caregivers often do not interpret NPS as a sign of unmet needs, such as underlying distress or pain. Left untreated, pain becomes an unmet need that will not be dealt with correctly. NPS are often

treated with psychotropic drugs, like haloperidol and lorazepam.²² Use of psychotropic drugs is associated with serious adverse events, such as increased cognitive decline, falls, extrapyramidal symptoms, cardiovascular events, and even death.²³⁻²⁵

To avoid inadequate treatment of an unmet need such as pain, neuropsychiatric symptoms/challenging behaviour like agitation or aggression should serve as a red flag and trigger further examination for pain as a potential cause. Next, a tailored (non)pharmacological treatment is possible.

Physical functioning

Physical functioning or Activities of Daily Living (ADL) refer to fundamental skills that are required to independently carry out self-care activities such as bathing, dressing, eating, and walking.^{26,27} The inability to perform ADL activities results in dependence on others and an increasing need for support from care services.

In dementia, ADL functioning is subjected to the progressive nature of the neuropathological changes which cause the disease. Therefore, a decline in ADL functioning is to be expected, especially in the more advanced stages of dementia.^{28,29} However, functional decline in dementia is a complex phenomenon. Apart from the dementia itself, various (indirect) causes can lead to functional impairment. For example, apathy or depression, medication use, such as psychotropic drugs, but also pain. Pain is known to interfere with ADL functions.³⁰⁻³²

However, it is unclear what the (added) effect of pain is on ADL functioning in persons with dementia.

Nursing home care setting in the Netherlands

Care for persons with advanced dementia is often centred in nursing homes, on special psychogeriatric wards. In 2021, approximately 290,000 people in the Netherlands are living with dementia.³³ An estimated 70,245 are living in a nursing home.³⁴

The integrated medical and paramedical care in the nursing home is provided by a multidisciplinary team. This team consists of, at least, a psychologist, occupational therapist, physiotherapist, and an elderly care physician.³⁵ The Netherlands is the only country in the world which has a medical specialty called 'elderly care medicine'.³⁶⁻³⁸

Additionally, trained nursing staff provides day-to-day care, 7 days a week, 24 hours a day, and they are also part of the multidisciplinary team. This team formulates an individual care plan for the resident, including advance care planning and treatment of intercurrent medical issues.

Pain assessment

Due to the complex interplay between dementia, pain, NPS, and ADL functioning, recognizing pain is challenging, especially when verbalizing pain is hampered.

The American Geriatric Society (AGS) formulated several verbal and nonverbal pain-related behaviours and changes in normal functioning which could indicate the presence of pain.³⁹ For example, sighing, moaning, increased pacing, aggression, and changes in sleep. Additionally, the AGS published guidelines with recommendations for accurate pain assessment in persons with dementia.³⁹ The most important method is via direct observation of the residents and preferably using observational measurement instruments. Over time, many observational measurement instruments have been developed, such as the PACSLAC-D or PAINAD.⁴⁰⁻⁴² However, the psychometric properties, like validity and reliability, of many of these instruments were not thoroughly tested.^{6,43} Furthermore, the existing tools are diverse and no universal tool is available. Although there is some agreement between the observational measurement instruments, there is great discrepancy in the way they are operationalized in clinical practice.⁴⁴

Objectives of this thesis

The primary aim of this thesis is to investigate the complex relationship between pain, neuropsychiatric symptoms, and ADL functioning in people with dementia. (Figure 1). This is important, as it may help in targeting treatment options; should we treat pain, neuropsychiatric symptoms, or start interventions to prevent/stabilize functional loss? The first part of this thesis focusses on unravelling this relationship, with specific attention to the effect of pain on ADL functioning.

The second part aims to investigate the psychometric properties of a new tool to measure pain in persons with dementia: Pain Assessment in Impaired Cognition (PAIC). This thesis focusses on the English as well as the Dutch research versions of the PAIC.

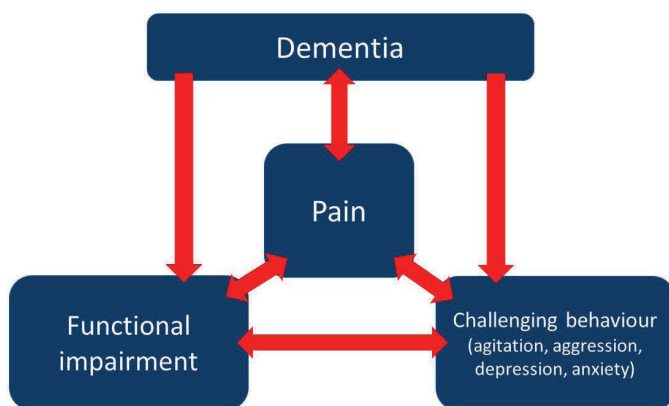


Figure 1. Interplay between dementia, pain, NPS, and ADL functioning

The main research questions in this thesis are:

Part I. Relationship between pain, neuropsychiatric symptoms, and ADL functioning

1. *What is the current state of evidence regarding the challenges of pain management in persons with dementia?*
2. *What is the strength of associations between pain, neuropsychiatric symptoms, and physical functioning in persons with dementia?*
3. *What is the relationship between the course of pain and change in ADL functioning, both generally and regarding specific ADL functions?*

Part II. Pain Assessment in Impaired Cognition: PAIC

4. *What is the content validity of the Dutch version of the Pain Assessment in Impaired Cognition scale?*
5. *What is the observer agreement on the individual 36 items of the Dutch version of the PAIC in a real-life nursing home setting?*
6. *What is the observer agreement and factor structure of each of the 36 items of the Pain Assessment in Impaired Cognition?*

Outline of this thesis

To address the objectives of this thesis, we performed both literature and clinical research. The first part of the thesis describes a literature review on the management of pain in persons with dementia (Ch. 2). It elaborates on four key perspectives: 1) effect of neuropathological changes on pain perception in dementia; 2) assessment of pain in dementia; 3) efficient treatment of pain; and 4) pain management.

In Chapter 3, a comprehensive systematic overview and meta-analysis of the strength of associations between pain, neuropsychiatric symptoms, and physical functioning is described, with special attention for the measurement of those three modalities.

Finally, in Chapter 4 the relationship between pain and ADL functioning in persons with dementia is investigated using a longitudinal study design.

In the second part of this thesis the psychometric properties of a new and improved observational measurement instrument (comprising 36 items) to measure pain in persons with dementia, Pain Assessment in Impaired Cognition (PAIC), is described. Observer agreement and factor structure, as well as the results of the validity and reliability study of all 36 items of the Dutch version of the PAIC are reported in Chapters 5, 6 and 7.

Finally, Chapter 8 presents a summary and a general discussion that reflects on the results presented in this thesis. General findings are put into context, methodological strengths and limitations are discussed, and implications for both clinical practice and research are described.

Last but not least, it reflects on the situation about Hans, the 67-year-old man with Lewy body dementia. We will indicate the steps that should be taken to reduce challenging behaviour, prevent loss of mobility, and ultimately improve his quality of life.

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