Original Study

Prevalence of Pain in Nursing Home Residents: The Role of Dementia Stage and Dementia Subtypes

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A B S T R A C T

Objectives: To study pain prevalence, pain type, and its pharmacological treatment in Dutch nursing home residents in relation to dementia subtype and dementia severity.
Design: Data were collected as part of the PAINdemiA study, an observational cross-sectional study conducted between May 2014 and December 2015.
Setting: Ten nursing homes in the Netherlands.
Participants: A total of 199 nursing home residents in various stages of dementia.
Measurements: We collected data on pain (by observation: MOBID-2 Pain Scale and by self-report scales), pain type, pain medication, dementia subtype, dementia severity (GDS), and demographic features.
Results: In the whole sample, the prevalence of pain was 43% (95% confidence interval 36%—50%) using the MOBID-2 Pain Scale. Regardless of regularly scheduled analgesics, approximately one-third of the residents with pain suffered from moderate to severe pain. Pain assessment with the MOBID-2 Pain Scale showed no difference in pain between dementia subtypes, but residents with more severe dementia experienced pain more often than those with less severe dementia (27% vs 15%). The prevalence of self-reported pain was significantly higher in residents with vascular dementia (VaD) (54%) compared with those with Alzheimer disease (18%) and other dementia subtypes (14%). Nociceptive pain was the predominant type of pain (72%) followed by mixed pain (25%). Acetaminophen was the most prescribed analgesic (80%).
Conclusion: Most of the participating nursing home residents had no pain; however, pain was observed more often in residents with severe dementia, whereas residents in the early stages of VaD self-reported pain more often that those with other dementia subtypes.
As one-third of the residents with clinically relevant pain had moderate to severe pain regardless of using pain medication, more focus should be on how pain management could use more tailored approaches and be regularly adjusted to individual needs.

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Pain is a common problem in people with dementia. Previous studies have reported that the prevalence of pain in people with dementia is approximately 50% and that pain is mainly caused by age-related musculoskeletal disorders like osteoporosis and arthritis.[1,2]

Pain can be divided into 2 types: nociceptive pain and neuropathic pain. Nociceptive pain is often associated with osteoarthritis, and it is considered the most prevalent pain type, whereas neuropathic pain, which can result from stroke and diabetes, is also a common phenomenon.[3] However, neuropathic pain has been barely explored in nursing home residents with dementia.[3] This is not surprising, considering that the diagnosis of neuropathic pain lies in the

expression of specific complaints and this ability might be limited in people with dementia.[3,4] As previous studies in the general population have reported higher pain intensities for people suffering from pain with neuropathic characteristics (eg, tingling, burning, or shooting) than for people suffering from pain without neuropathic characteristics,[5] recognizing pain with neuropathic characteristics is a pivotal point in providing optimal pain treatment in nursing home residents with dementia.

Pain assessment in nursing home residents with dementia is a challenging task.[6] In the earlier stages of dementia, pain assessment is usually possible via self-report of pain, whereas in the later stages, self-report becomes impossible. In these stages, pain assessment depends on observation of pain and detection of pain-related behavior.[7] Dementia-specific assessment tools are helpful in detecting these pain-related behaviors, although these tools are not able to distinguish pain from other causes of discomfort, and they cannot make a clear distinction among the different pain types.[6,8] Yet, the challenge of accurately identifying pain remains necessary for effective pain treatment.[9]

Some studies indicate that residents with severe dementia are particularly at risk to suffer from pain,[10,11] whereas other studies found that pain prevalence did not differ among residents in different stages of dementia.[12] Dementia-specific neuropathological changes may be responsible for alterations in pain perception.[1,13] Disturbances in the pain system by white matter lesions may increase the pain experience in people with vascular dementia (VaD) compared with other dementia subtypes, whereas gray matter atrophy may lead to a decrease in pain experience in people with Alzheimer disease (AD) and frontotemporal dementia (FTD).[13–15] Nevertheless, the current body of research is ambiguous, as the findings on pain experience in dementia subtypes are inconsistent, and the direction of the impact of neuropathology may differ in dementia subtypes.[16]

The aim of this study was to determine and compare pain prevalence, pain type, and its pharmacological treatment in Dutch nursing home residents in relation to dementia subtype and dementia severity.

Methods

Design

A cross-sectional observational study of nursing home residents was carried out as part of the PAINdemiA study. Data were collected from May 2014 to December 2015, and all measurements of a resident were administered within a time frame of 1 week. The full protocol has been published elsewhere.[17]

Study Population

We invited all residents (n = 679) who were living at a dementia special care unit in one of the participating Dutch nursing homes (n = 10) to participate in the study. Once a nursing home had agreed to participate, legal representatives of all residents were informed and asked to give consent. Inclusion criteria were aged 60 years or older, being diagnosed with dementia, and having a signed informed consent form by the legal representative. Residents were excluded when they had a diagnosis of Huntington disease, Parkinson disease dementia, or alcohol-related dementia, or when they suffered from cognitive impairment due to psychiatric disorders or intellectual disabilities. This study was approved by the Medical Ethics Review Committee of the VU University Medical Center (Amsterdam, The Netherlands).

From the source population for this study (679 nursing home residents who were living at a dementia special care unit in one of the participating nursing homes), we could finally include a sample of 199

residents. We received a signed informed consent for 219 residents (32.3%), of these residents 20 (2.9%) were subsequently excluded because they did not meet the inclusion criteria or moved or died before the start of the assessment. For 252 residents, we did not receive any response, and 208 residents refused to participate (Figure 1).

Measurement and Residents' Characteristics

Pain was assessed by different methods that were partly adjusted to the level of communication of the resident. In all residents, the Mobilization Observation Behaviour Intensity Dementia (MOBID-2) Pain Scale was used to assess pain. The MOBID-2 is a 2-part, nursing staff–administered observational instrument: it assesses immediate pain behaviors in response to 5 standardized active, guided movements of different body parts during morning care, and it assesses pain behaviors that might originate from internal organs, head, and skin over time.[18,19] Using a numeric rating scale, the overall pain intensity of the MOBID-2 ranges from 0 to 10, and an overall score of ≥3 is regarded as clinically relevant pain.[19] Studies on the psychometric properties of the MOBID-2 have shown good reliability, validity, and feasibility in clinical practice.[18,19] As the frequency distribution of this scale was skewed, MOBID-2 scores were categorized into 3 groups: no pain (0–2), mild pain (3–4), and moderate-severe pain (5 and above).

In *residents who were able to communicate about the presence of pain,* the researcher also asked the resident about pain through self-report. Depending on the resident's understanding of self-report scales, as judged by the researcher, the Numeric Rating Scale (NRS), Verbal Descriptor Scale (VDS), and/or Faces Pain Scale Revised (FPS-R) were used to measure pain.[20–22] The NRS ranges from 0 to 10, and it has a cutoff score of 4 and more for clinically relevant pain. The VDS has 5 ordinal categories (no pain, mild pain, moderate pain, severe pain, worst pain possible), and pain categorized as "moderate pain" or more is regarded as clinically relevant pain. The FPS-R consists of 6 drawings of faces ranging from a neutral face to a grimacing face. From the third face onward, pain is regarded as clinically relevant.[23]

In *residents with difficulties to communicate their pain,* as judged by the researcher, the Pain Assessment IN Advanced Dementia Scale (PAINAD) was used to assess pain.[24] The PAINAD is a brief and easy-to-administer observational scale especially used in people with advanced dementia. It assesses 5 behaviors related to pain, and each of these is rated on a 3-point scale (0–2). The total score ranges from 0 to 10, and a cutoff score of 2 has been recommended as indication for the
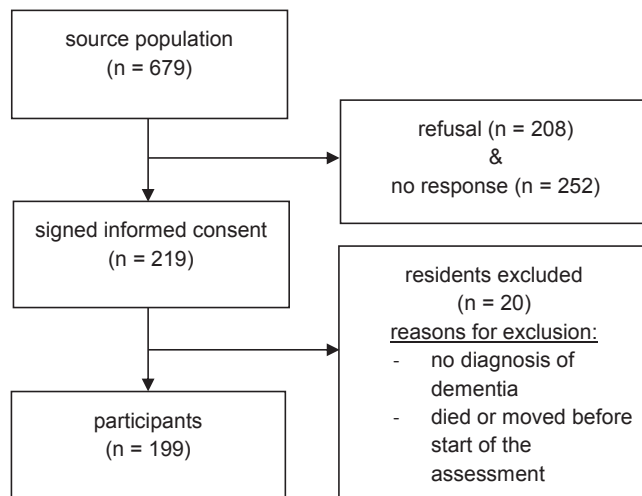

Fig. 1. Flowchart of inclusion.