When Pain Memories Are Lost: A Pilot Study of Semantic Knowledge of Pain in Dementia

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Setting. Acute general hospital medical wards for older people.

Subjects. People with dementia (N = 26) and control participants (N = 13).

Methods. Two subtests of semantic memory for pain: 1) Identifying painful situations from a standardized range of pictures; 2) Describing the concept of pain. Participants also indicated whether they were in pain or not, were observed for pain (PAINAD scale) and completed the Wong–Baker FACES scale to indicate pain severity.

Results. Compared with the control group, people with dementia were less able to identify painful situations and used fewer categories to define their concept of pain. In turn, the performance on these two measures was related to the reported presence and, albeit less strongly, to the reported severity of pain, indicating that a reduction in semantic memory for pain is associated with a decline in reported pain.

Conclusions. This study is the first to show that semantic memory for pain is diminished in dementia patients. When using clinical pain tools, clinicians should consider these effects which may bias clinical pain ratings when they evaluate and manage pain in these patients. This might improve the recognition and management of pain in people with dementia.

Key Words. Pain; Dementia; Semantic Memory; Pain Tools

Introduction

Clinical pain studies in people with dementia have indicated that they report less pain [1–3]. This parallels the progression of the disease; reported pain decreases with increasing dementia severity. In addition, people with dementia receive less pain medication, even when they have similar painful conditions as cognitively intact patients [4].

Abstract

Objective. It has been documented that pain in people with dementia is often under-reported and poorly detected. The reasons for this are not clearly defined. This project aimed to explore semantic concepts of pain in people with dementia and whether this is associated with clinical pain report.

Design. Cohort study with nested cross-sectional analysis.
One potential explanation for these observations is that brain regions involved in the processing of pain degenerate in dementia [5]. For example, Alzheimer’s disease (AD) affects the medial pain pathway which has been associated with disrupted pain processing; this may result in reduced clinical pain ratings [3]. Experimental studies provide evidence for altered pain processing, showing normal pain detection but increased pain tolerance in people with AD [6]. However, these findings are challenged by the observation that people with AD do not display diminished activation of the medial and lateral pain system following painful stimulation, and they show an increase in brain activity following mechanical pressure pain compared with controls [7]. This has been interpreted as evidence against a decline in pain processing in dementia.

An alternative explanation is that people with dementia do not experience less pain, but that cognitive impairment limits the ability to recognize and report pain. In judging pain severity, we rely on previous experiences and knowledge of pain, underpinned by episodic memory (i.e., memories of specific events) and semantic memory (i.e., wider factual conceptual knowledge). The deterioration of these memory functions may therefore impair the ability to report pain. For example, severe episodic memory impairment could explain how reduced clinical pain ratings in dementia patients are actually the result of the pain being forgotten. Previous studies do not, however, support this [8,9]. As semantic memory declines in dementia [10], it could be hypothesized that the concept of pain may no longer be intact in these patients. To our knowledge, studies thus far have not considered whether people with dementia still have intact semantic knowledge regarding the concept of pain. Furthermore, we do not know whether or how impaired semantic knowledge influences clinical pain report.

Our first aim was to explore the semantic knowledge of pain in people with dementia. To examine this, we measured the ability to recognize pictures of a painful situation and the estimate of pain severity inflicted by these situations. We then asked for a description of the concept of pain and for examples of painful conditions. We hypothesized that a decline in semantic memory for pain would be reflected in fewer correctly identified pain pictures, lower pain estimates, and a less detailed description of pain. Our second aim was to examine the hypothesis that reduced semantic knowledge of pain is associated with lower general cognitive function and with lower clinical pain ratings.

Methods

Participants were recruited from an acute hospital in north London (UK), where they were participating in a cohort study examining pain and behavioral problems in older people with dementia after unplanned acute hospitalization for medical problems [11]. Twenty-six people (nine males) participated in this sub-study (mean age 86.9 ± 6.8). Inclusion criteria were people over the age of 70 years with an unplanned acute hospital admission under the care of a geriatrician, able to give verbal consent or a carer/consultee able to give assent and sufficient English to complete study ratings. The Abbreviated Mental Test Score [12] was used to screen for cognitive impairment. A score of ≤7 led to further assessment with the Mini Mental State Examination (MMSE, mean score 13.96 ± 6.57, range 0–24) [13]. History on cognition and function was gathered from hospital notes, carers, and family members (where available). Dementia was then diagnosed according to operationalized Diagnostic and Statistical Manual of Mental Disorders (DSM)-IV criteria. Patients were excluded if they had a persistent delirium throughout their admission and no previous dementia diagnosis. Patients did not receive a financial incentive for participation. This study was approved by the ethics committee of Central London-REC3 (Project reference 10/H0716/79).

Control Group

Thirteen age- and sex-matched elderly people were included as a control group (mean age 83.3 ± 4.9, six males), drawn from a study on age effects and neuropsychological correlates of semantic memory for pain (unpublished). This was approved by the local Institutional Review Board in accordance with the Declaration of Helsinki. All participants were free of conditions causing cognitive impairment (history of stroke, severe depression, or neurodegenerative disorders). The control group consisted of participants who needed physical therapy, either in a Dutch physical therapy practice in Nijmegen or in a rehabilitation ward of a care facility, and participants who were acquaintances of the researcher. The same researcher (HH) was involved in collecting the control data and the dementia patients.

Current Pain in Dementia

Patients with dementia were first asked whether they were in pain at the moment. They then indicated their current pain intensity, using the Wong–Baker FACES Pain Rating Scale (FACES scale). Pain was observed using the Pain Assessment in Advanced Dementia Scale (PAINAD), a behavioral scale developed to assess pain in people with dementia who are unable to self-report [14]. A total of five behavioral indicators of pain were scored on a 0–2-point rating scale during movement (either from bed to chair or repositioning in bed). As this scale is based on behavioral observations, outcomes should not be influenced by loss of semantic memory; hence, no association with our semantic memory for pain test was expected.

Semantic Memory

The first part of the test for Semantic Memory for Pain (SMP) consists of 16 pictures. Eight pictures showed a painful situation, five a related non-painful situation, and three an unrelated (neutral) situation. The pictures that represented painful and related (non-painful) situations were adopted from a previously validated set [15]. The
selected pictures varied in terms of arousal (i.e., the level of excitement of a stimulus; low, medium or high level of arousal) and the type of pain represented (thermal or mechanical). The three unrelated pictures showed neutral actions (typing, knitting, and kneading dough). Patients were asked to indicate whether a picture represented a painful situation or not. Scoring was as follows: “true positives” (correct identification of a pain picture), “true negatives” (correct rejection of a non-painful picture), “false negatives” (incorrect rejection of a pain picture), and “false positives” (incorrect identification of a non-painful picture). In case of “true positive,” patients were asked to indicate the level of pain they imagined that situation would cause, using the FACES scale. Where a participant could not indicate whether or not a picture represented pain, the response was coded as “no response.” The second part of the SMP test consists of two open-ended questions: Q1. What is pain? and Q2. Can you name different types of pain? Responses were scored using open and axial coding [16].

**Statistical Analysis**

To examine whether semantic memory for pain is diminished in dementia, Mann–Whitney *U* tests were performed to examine group differences in performance on the pain pictures test, the average expected level of pain inflicted by the painful situations, as well as the coded answers (average number of categories) to the two questions. Potential group differences in these different categories were examined using Pearson chi-square tests.

Spearman rank correlations were calculated to examine the relationship between general cognition (MMSE), semantic memory for pain (SMP test), pain observations (PAINAD), and between the SMP test and clinical pain report (point-biserial correlations for the presence of pain variable). Data were analyzed using SPSS 19.0 (IBM, Chicago, IL). As specific directions of the results can be predicted based on previous studies (e.g., showing reduced semantic knowledge as well as reduced pain reports in dementia patients), all analyses were performed one-tailed. Correlations were interpreted according to established guidelines [17] (weak: < 0.3; moderate: 0.3–0.5; high: ≥ 0.5).

**Results**

No significant differences were present between the two groups with regard to age (t(37) = −1.68, *P* = .10) or sex (χ²(1) = 0.49, *P* = .49).

**Group Differences**

There were significant differences with regard to the number of true positives, true negatives, and false negatives of the pain pictures and for the coded answers (Table 1). People with dementia made fewer true positives, fewer true negatives, and more false negatives. The coding of the open-ended questions resulted in the following categories. For Q1; affective aspects (unpleasantness) of pain, cause or nature of pain, emotional reaction to pain, an abnormal state, or a synonym of pain. For Q2; location of pain, type of pain, cause of pain, or a synonym of pain. People with dementia gave a less detailed description of the concept of pain (Q1) and used descriptions of affective aspects and the cause or nature of pain less often. For Q2, people with dementia described pain location less often.

### Table 1  Performance of the dementia and control group on the semantic memory for pain test

<table>
<thead>
<tr>
<th>Test</th>
<th>Dementia Group</th>
<th>Control Group</th>
<th>Statistical Test</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Pain picture test</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>True positives</td>
<td>5.19 (2.71)</td>
<td>7.62 (0.51)</td>
<td><em>U</em> = 64.00, <em>Z</em> = −3.23, <em>P</em> = 0.001</td>
</tr>
<tr>
<td>True negatives</td>
<td>4.27 (2.95)</td>
<td>6.54 (1.33)</td>
<td><em>U</em> = 94.50, <em>Z</em> = −2.25, <em>P</em> = 0.05</td>
</tr>
<tr>
<td>False positives</td>
<td>1.73 (1.99)</td>
<td>0.92 (0.95)</td>
<td><em>U</em> = 198.50, <em>Z</em> = 0.91, <em>P</em> = 0.19</td>
</tr>
<tr>
<td>False negatives</td>
<td>1.11 (1.61)</td>
<td>0.15 (0.38)</td>
<td><em>U</em> = 229.00, <em>Z</em> = 2.09, <em>P</em> = 0.05</td>
</tr>
<tr>
<td>No answer</td>
<td>3.69 (5.76)</td>
<td>0.77 (1.17)</td>
<td><em>U</em> = 205.00, <em>Z</em> = 1.17, <em>P</em> = 0.15</td>
</tr>
<tr>
<td>FACES score</td>
<td>3.92 (0.56)</td>
<td>3.69 (0.49)</td>
<td><em>U</em> = 156.00, <em>Z</em> = 1.25, <em>P</em> = 0.11</td>
</tr>
<tr>
<td><strong>Q1 categories</strong></td>
<td>0.88 (0.86)</td>
<td>1.46 (0.52)</td>
<td><em>U</em> = 101.50, <em>Z</em> = −2.26, <em>P</em> = 0.05</td>
</tr>
<tr>
<td>Affective aspects</td>
<td>3 (11.5%)</td>
<td>8 (61.5%)</td>
<td>*χ²(1) = 10.70, <em>P</em> = 0.001</td>
</tr>
<tr>
<td>Cause or nature</td>
<td>7 (26.9%)</td>
<td>7 (53.8%)</td>
<td>*χ²(1) = 2.73, <em>P</em> = 0.05</td>
</tr>
<tr>
<td>Emotional reaction</td>
<td>3 (11.5%)</td>
<td>1 (7.7%)</td>
<td>*χ²(1) = 0.14, <em>P</em> = 0.60</td>
</tr>
<tr>
<td>An abnormal state</td>
<td>4 (15.4%)</td>
<td>1 (7.7%)</td>
<td>*χ²(1) = 0.46, <em>P</em> = 0.45</td>
</tr>
<tr>
<td>Synonym</td>
<td>6 (23.1%)</td>
<td>2 (15.4%)</td>
<td>*χ²(1) = 0.31, <em>P</em> = 0.46</td>
</tr>
<tr>
<td><strong>Q2 categories</strong></td>
<td>0.77 (0.71)</td>
<td>1.0 (0.41)</td>
<td><em>U</em> = 127.50, <em>Z</em> = −1.49, <em>P</em> = 0.11</td>
</tr>
<tr>
<td>Pain location</td>
<td>5 (19.2%)</td>
<td>7 (53.8%)</td>
<td>*χ²(1) = 4.875, <em>P</em> &lt; 0.05</td>
</tr>
<tr>
<td>Type of pain</td>
<td>5 (19.2%)</td>
<td>2 (15.4%)</td>
<td>*χ²(1) = 0.09, <em>P</em> = 0.38</td>
</tr>
<tr>
<td>Cause of pain</td>
<td>8 (44.4%)</td>
<td>4 (30.8%)</td>
<td>*χ²(1) = 0.00, <em>P</em> = 0.50</td>
</tr>
<tr>
<td>Synonym</td>
<td>2 (7.7%)</td>
<td>0 (0%)</td>
<td>*χ²(1) = 1.05, <em>P</em> = 0.44</td>
</tr>
</tbody>
</table>

Values represent means (±SD) with the exception of the Q1 and Q2 subscores, which represent frequencies (%). Mann–Whitney *U* tests were employed to test for group differences when means and SDs are presented; Pearson chi-square tests were employed to test for group differences in frequencies.
A further examination of the individual scores revealed that, although most dementia patients performed the task acceptably well (i.e., above-chance level on the number of true positives or above-chance level on the total number correct [true positives + true negatives]), four participants were, overall, unable to respond to these questions, and thus obtained scores of 0 or 1. Group comparisons, restricted to patients with above-chance performance, still revealed significant group differences with regard to the number of true positives ($U = 64.00, Z = -2.82, P < 0.01$), false negatives ($U = 207.00, Z = 2.48, P < 0.05$), true negatives ($U = 94.50, Z = -1.68, P < 0.05$), and the number of categories used for Q1 ($U = 98.00, Z = -1.67, P < 0.05$), whereas a trend was present for the number of false positives ($U = 188.50, Z = 1.61, P = 0.054$).

**The Presence and Intensity of Pain**

Eleven people with dementia reported the presence of pain, and 13 reported they were not in pain; two were unable to answer and were excluded from further analyses. An additional seven participants (one who did, six who did not report the presence of pain) did not comprehend the FACES scale and could not provide an indication of the clinical pain severity; among these patients were three patients who performed badly on the picture identification task as well. Analyses of pain severity were therefore restricted to 17 people with dementia. The association between semantic memory and ability to comprehend and use the FACES scale (coded as intact [score 1] or disturbed comprehension [score 0]) was examined using point-biserial correlations.

**Correlations Between the MMSE, PAINAD, and SMP**

Strong, significant correlations were found between the MMSE and the SMP—true positives and SMP—true negatives and false negative responses, as well as the average Q1 and Q2 scores. In all instances, a higher MMSE score was associated with better performance on the picture test and more categories given for Q1 and Q2 (Table 2).

The PAINAD was not related to any of the SMP variables but was significantly (but moderately) correlated with the current pain severity (FACES scale: $\rho = 0.40, P = .05$), indicating that this scale was useful in indicating pain severity and not influenced by limitations in semantic memory.

**Correlations Between SMP and Clinical Pain**

The presence of pain as indicated by the patient was significantly and moderately associated with the number of true positives on the picture test (Table 2). Trends were found with a moderate association between the presence of pain and the total number of categories used to answer Q1 ($P = 0.055$) as well as a weak association between the presence of pain and the number of true negatives on the picture test ($P = 0.09$). In all instances, the presence of pain was associated with better performance. The current pain severity score revealed a marginally significant moderate correlation ($P = 0.09$) with the number of false negatives of the pain picture test; a higher current pain score was associated with fewer false negatives on this test. A higher FACES current pain intensity score was significantly and strongly associated with lower estimated pain induced by the painful situations.

**Comprehension of the FACES Scale**

Moderate correlations were found between comprehension of the FACES scale and the number of true positives ($\rho = 0.46, P < 0.05$) and the number of true negatives ($\rho = 0.40, P < 0.05$), indicating that better performance on the picture task was associated with the ability to use the FACES scale. The correlation between the ability to comprehend the FACES scale and the MMSE was not significant ($\rho = 0.13, P = 0.27$).

<table>
<thead>
<tr>
<th>Table 2</th>
<th>Correlations between the MMSE, current presence and intensity of pain, the PAINAD, and the semantic memory for pain test</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Test</strong></td>
<td><strong>True Positives</strong></td>
</tr>
<tr>
<td>MMSE</td>
<td>0.53**</td>
</tr>
<tr>
<td>Presence pain</td>
<td>0.37*</td>
</tr>
<tr>
<td>FACES-score</td>
<td>0.11</td>
</tr>
<tr>
<td>PAINAD</td>
<td>–0.09</td>
</tr>
</tbody>
</table>

* $P < 0.05$; ** $P < 0.01$; *** $P < 0.001$.

FACES = Wong–Baker FACES Pain Rating Scale; MMSE = Mini Mental State Examination; PAINAD = Pain Assessment in Advanced Dementia.

Spearman correlations are presented.
Discussion

Our aim was to explore semantic memory for pain in people with dementia and its association with clinical pain ratings. Compared with a group of age- and sex-matched controls, people with dementia performed worse on the pain picture identification task. In addition, significant alterations were found in the concept of pain: people with dementia less frequently used affective descriptions or causes of pain. Also, pain was less frequently described by pain location. These changes in pain semantics were in turn related to pain report: patients who confirmed the presence of pain also performed better on the number of pain pictures correctly identified as either painful or non-painful and used more extensive descriptions of the concept of pain. Similarly, clinical pain was rated as less severe in cases of an increased failure to identify pain pictures. Finally, the ability of patients with dementia to use the FACES scale was positively related with the number of pain pictures correctly identified.

Overall, these findings support our hypothesis that pain semantics are diminished in dementia, indicating that questions concerning pain may be interpreted differently as a result of loss of semantic knowledge. Furthermore, this decline is related to altered clinical pain report. These findings have important implications. They suggest that the diminished pain ratings observed in people with dementia may be secondary to semantic memory loss. In addition, the concept of pain is qualitatively different in people with dementia, therefore, a question such as “are you in pain at the moment” may be interpreted differently compared with the intention conveyed by the question. We cannot exclude the possibility that pain experience is altered in this population, but our findings suggest that part of the decline in clinical pain rating may be due to underlying semantic memory deficits.

One exception is the result found for estimated pain based on the pain pictures; a strong correlation was present where higher pain estimated from the pain pictures was associated with lower current pain intensity ratings (which is generally associated with more severe dementia). This may have occurred because the estimated pain ratings were based only on those pictures that were correctly identified as being painful; many patients failed to identify all of the pain pictures correctly. The pictures that were not identified by the patients as painful were not considered in this particular analysis. It is likely that assigning a score of 0 for pain to those pictures would have altered the correlation between the pain estimates and pain severity. Alternatively, an exaggerated response to pain and non-painful sensory experiences has been reported in semantic dementia patients [18], presumably because they are no longer aware of potentially adverse consequences of situations or objects [19]. It is possible that in semantic memory loss, patients do not anticipate or expect pain, or may not even recognize the sensation, leading to increased emotional reactions such as exaggerated facial expressions [20] and increased pain estimates. However, these examples are all based on reactivity to acute painful stimulation and may actually reflect “reduced audience inhibition effect” [21], secondary to loss of higher cortical inhibition.

Limitations

Our findings of an association between semantic memory and clinical pain report are based on correlation, and no causal relationship can be assumed. It may be that the relationship with semantic memory merely reflects the cognitive deterioration present in all patients, not an association unique to semantic memory, as indicated by the strong correlations between the SMP and the MMSE as well as the fact that some participants were unable to respond to the SMP questions and the pain assessment. However, the number of false negatives on the SMP was associated with the FACES score but not with the MMSE. This indicates that it is not just the underlying decline in general cognitive function, which leads to the relationship between semantic pain measure and clinical pain. Also, the ability to comprehend the FACES scale was moderately associated with our SMP indices but not to the MMSE. These findings support the use of the SMP test as a potential correlate of clinical pain report. In addition, the correlations between the SMP and the MMSE are similar to those reported between the MMSE and other semantic memory tests in dementia [22,23]. Nonetheless, the small sample size, the researcher not being blinded to the participants’ status, together with the fact that we compared (British) dementia patients with a control group of a different nationality (Dutch) necessitates further research in larger samples. Specifically the latter point is crucial, since we cannot rule out whether cultural differences might have affected SMP performance. Whereas these influences may be less pronounced for the identification of the pictures, which were drawn from a previous validated sample [15], specifically the answers given to Q1 might be prone to cultural effects.

Implications for Future Research

To summarize, future studies are needed in larger samples, conducted within single countries in order to eliminate cultural influences. Considering the difficulties patients with dementia had in understanding the FACES scale, it is crucial that comprehension of this scale is established prior to using it for pain assessment purposes in patients. One way to do so is to ask the patients to order the pain faces from zero to most severe. Finally, an intriguing finding was the observation that the SMP test was not associated with the PAINAD score, indicating that the PAINAD can be used as a reliable indicator of (behavioral responses to) pain that is unaffected by semantic memory loss. This necessitates the inclusion of behavioral indicators of pain next to clinical pain reports when assessing pain in patients with dementia.

Conclusion

To our knowledge, this is the first study to focus on potential changes in semantic memory for pain in relation to
clinical pain report in dementia. Our results confirm an association between clinical pain and semantic memory, indicating that when assessing pain in people with dementia, impaired semantic memory may limit the ability to report pain. Further, larger studies are needed to increase our understanding of this association, and eventually, to develop clinical pain tools which take this into account. This would significantly improve the recognition and management of pain in people with dementia.

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