How do healthcare workers judge pain in older palliative care patients with delirium near the end of life?

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Abstract

Context: Pain and delirium are commonly reported in older people with advanced cancer. However, assessing pain in this population is challenging and there is currently no validated assessment tool for this task.

Objectives: This retrospective cohort study was conducted to understand how healthcare workers (HCWs; nurses and physicians) determine that older cancer patients with delirium are in pain.

Methods: We reviewed the medical records of consecutive palliative care inpatients, 65 years of age and above (n = 113), in order to identify patient-based cues used by HCWs to make pain judgments and to examine how the cues differ by delirium subtype and outcome.

Results: We found that HCWs routinely make judgments about pain in older patients with delirium using a repertoire of strategies that includes patient self-report and observations of spontaneous and evoked behaviour. Using these strategies, HCWs judged pain to be highly prevalent in this inpatient palliative care setting.

Conclusion: These novel findings will inform the development of valid and reliable tools to assess pain in older cancer patients with delirium.

Keywords: Cancer pain, older people, delirium, palliative care, pain assessment, chart audit

Running Title: Pain in older cancer patients with delirium

Most older people with advanced cancer report moderate to severe pain that diminishes quality of life (1). In the final stages of the disease, up to 85% of older people will also develop delirium (2), an acute organic brain disorder marked by impaired consciousness and awareness as well as abnormalities of cognition and perception (3). There are three subtypes of delirium: hypoactive, which presents with confusion and sedation; hyperactive, which presents with hallucinations, delusions, agitation and disorientation (3, 4, 5); and a mixed presentation with features of both the hyperactive and hypoactive subtypes. For each of these subtypes, the outcome may be characterized as terminal, in which delirium continues until death, or reversible, in which it resolves before death (6). Both cancer pain and delirium at the end of life are associated with profound negative psychological and physiological consequences for patients (7, 8), as well as significant distress for family members (9, 7). Despite their high prevalence, the aging of the population (10), and the recognition that cancer is a disease of older people (11), much remains to be learned about cancer pain and delirium.

Furthering our knowledge depends on the availability of validated pain assessment strategies; however, assessing pain in older cancer patients with delirium presents many challenges (8, 9). Primary among these is that delirium may interfere with the self-report of pain. For example, some patients with hypoactive delirium may be unable to communicate verbally. Conversely, some patients with hyperactive delirium, who may be able to verbalize, may provide self-reports that are incoherent or difficult to interpret due to the presence of hallucinations or delusions. Another challenge is that the behavioral manifestations of pain and delirium may overlap, complicating observational assessment. For instance, guarding and grimacing may indicate pain or agitation or both. Differentiation of the underlying cause of behavioral cues is difficult (12). Finally, the ways in which the well-documented repertoire of pain cues (13) may change as a result of the widespread brain dysfunction associated with delirium (14, 15) or other changes associated with impending death and advanced disease (16, 17) are unknown. Established observational pain scales were not developed for this population and may not be sensitive to these assessment challenges (18). A measure developed and validated specifically for these patients is not currently available.

Despite these assessment challenges, healthcare workers (HCWs) believe that most patients with cancer-related delirium experience pain (19), and, in one study, they rated pain during delirium with agitation as more intense than pain during delirium without agitation (9). Importantly, HCWs' pain judgments impacted management, including the administration of opioid analgesics (9, 19). It is not clear how these HCWs judged pain or differentiated it from agitation. Studies in other populations have shown that pain judgments are based on a complex weighting of multiple sources of data, including patient self-report, behavior, and medical evidence (21, 22, 23). Similar complexity would be expected in the present patient population.

Understanding how HCWs determine that older cancer patients with delirium are in pain is a critical first step to improving pain assessment and management for this vulnerable group. To date, studies designed specifically to identify patient-based cues used by HCWs to make pain judgments and to examine how cues differ by delirium subtype and outcome have not been reported. This retrospective cohort study was conducted to address this knowledge gap by examining HCWs' judgments of cancer pain and delirium in older palliative care inpatients.

Materials and Methods

Participants and setting.

We reviewed the medical records of consecutive patients, 65 years of age and above, admitted to the Harold and Shirley Lederman Palliative Care Centre at the Princess Margaret Cancer Centre, University Health Network in a one-year period. Patients diagnosed with delirium via clinical interview during their admission were eligible for inclusion in the current study. The Lederman Centre is a 12-bed acute palliative care inpatient unit for patients with cancer. Approximately 350 patients are admitted yearly, with an average length of stay of 11 days; 50% of patients die on the unit, 30% are discharged home, and 20% are transferred to other units, predominantly community palliative care units or hospices (23).

Data Collection

Data were collected using a uniform electronic data extraction template. Unanticipated scenarios not included in the training were discussed with the research team until consensus about coding was reached. Abstractors were blind to the study's specific objectives but were aware that it was about pain and delirium. Each chart was reviewed by one abstractor, either a registered nurse or clinical research associate, who received training prior to reviewing the charts and all categorizations were subsequently reviewed by L. Gagliese.

Demographic and Medical Data. The demographic and medical data extracted included age, sex, marital status, education, ethnicity, time since cancer diagnosis, cognitive status at admission, length of admission in days, and medications administered each day. Comorbidities and the total number of conditions were recorded. These were further classified into conditions often associated with pain (e.g., osteoarthritis (24)) and those not usually associated with pain (e.g., hypertension). Strongest analgesic class administered was categorized according to the World Health Organization (WHO) analgesic ladder (25): opioid ± non-opioid (e.g., nonsteroidal anti-inflammatory drugs, adjuvants) analgesics; non-opioid analgesics only; and no analgesics. All notes from admission to either discharge or death were reviewed.

Delirium. Patients were classified as having delirium if the notations indicated the patient received this diagnosis based on clinical interview by a palliative care physician or psychiatrist. All notations regarding the type of delirium (hyperactive, hypoactive, or mixed) were recorded. Delirium was further classified as reversed (resolved prior to death or discharge) or terminal (continued until death) based on chart notations subsequent to clinical interviews. Cognitive status was evaluated daily.

Pain. Patients were classified as having pain on any day that the notes indicated that the person was in pain. Multiple notations of pain on the same day were scored as one day in pain. Similar rubrics were used to code “unable to judge pain” and “no pain.” All notes made by nurses or physicians describing pain assessment, characteristics, and behavioral expressions were extracted. This study was approved by the University Health Network Research Ethics Board.

Data Analysis

Prior to analysis of the outcomes of interest, comparisons between the two abstractors on all variables were conducted using t-tests for continuous variables and χ^2 tests for categorical variables to assess consistency of abstraction and identify any systematic biases due to abstractor. There were no differences between the abstractors on any variable; therefore all subsequent analyses were conducted pooling across abstractors.

Participant demographic and medical data. Descriptive statistics (means, standard deviations, frequencies) were calculated for the demographic and medical variables. The prevalence of delirium, its subtypes, and outcomes were calculated.

Pain and delirium. Content analyses of the clinical notations were undertaken to identify the rates of charting pain, ability to judge pain, pain assessment strategies employed and behavioral indicators of pain. The relationship between assessment strategy employed (e.g., patient self-report versus behavioral observation by HCW) and pain judgment was assessed using χ^2 tests. Pain-related notations were compared across patients with different delirium subtypes and outcomes.

Results

Participants

During the 1 year review period, 169 patients ≥65 years old were admitted to the Lederman Palliative Care Centre. Twenty (11.8%) were excluded due to missing or incomplete information on cognitive status. Thirty-six (21.3%) were excluded because the patients did not experience delirium during the admission. Therefore, this paper reports on 113 (66.9%) patients who were diagnosed with delirium (Table 1). Average age was 75.5 ± 6.8 years (range: 65 to 91 years), and 47.8% were women. A quarter of the patients had delirium on the day of admission, and the majority had onset within 3 days. Hypoactive delirium was most common, although hyperactive and mixed presentations were also seen. Most of the patients experienced terminal delirium and died during the admission.

Chart notation content analysis

Clinical notes from 804 admission days were abstracted. On 38 days (4.7%), there were no chart notations about pain. On 58 (7.2%) days, HCWs recorded being unable to assess pain or that the patient was nonresponsive. Therefore, 708 assessments days were available for content analyses. Three (0.4%) notes indicated that a family member had reported the patient was in pain. Information regarding how family members made this judgment or HCWs verified it was not recorded. On a large majority of days (86%; 609/708), assessment was based on patient self-report (e.g., patient “denies,” “reports,” or “does not complain” of pain). On the remaining 13.6% (96/708) of assessment days, observational pain cues guided HCWs’ decisions.

Grouping self-report and observational assessments together, it was more likely for the notes to indicate that patients were experiencing pain than that they were not in pain (61.8% versus 38.2%; $p \leq 0.0001$). This was maintained when considering self-report and behavioral observation separately (Table 2). However, assessments based on observation were more likely than those based on patient self-report to indicate the patient was in pain (78.1% versus 59.3%; $p \leq 0.0001$; Table 2).

Examination of pain judgments based on behavioral observation revealed two major assessment strategies: observation of spontaneous behaviors (67.7%; 65/96) and observation of behaviors elicited by potentially painful experiences, such as repositioning or movement (32.3%; 31/96; Table 3). In 42.7% of observational assessments, HCWs did not record the specific cues used to determine the presence of pain. Instead, they wrote general behavioral impressions, such as “no obvious sign of pain” or “looks comfortable” or simply noted that the patient had “pain with repositioning” or “reacts to painful stimuli.”

Specific behavioral pain cues were described in 57.3% of observational assessments and were equally likely whether behaviors were spontaneous or elicited. For both types of assessment, the most common behavioral signs recorded were vocalizations, such as “moaning” or “groaning” (65.5%), and the facial expression “grimacing” (27.3%). See Table 3 for details of specific pain cues. Observational cues did not differ by delirium subtype or outcome.

Discussion

To our knowledge, this is the first study to examine HCWs' judgments about pain in older cancer patients with delirium on each day of admission to an acute palliative care unit. We found that judgments were based primarily on self-report when patients were able to verbally communicate, and on observation of behavioral cues, such as vocalizations and facial expressions, when patients could not verbally self-report. Both spontaneous behaviors and those exhibited during potentially painful experiences, such as repositioning or movement, were considered in assessments. These strategies did not differ by delirium subtype or outcome and were consistent with clinical guidelines (26) regarding pain judgments in other nonverbal populations.

Consistent with our previous studies in the palliative care setting (27), most of the patients were judged to have pain at some point during their admission. Presence of pain did not differ by delirium subtype. Interestingly, Bruera et al (9) reported differences in nurses' pain intensity ratings by delirium subtype, with more intense pain attributed to patients with agitation than those without agitation. However, their study is not directly comparable to the present one as different aspects of pain were examined. Bruera et al (9) examined HCWs' judgments of pain intensity whereas we examined their judgments of pain presence or absence. It is possible that the strategies used to judge these aspects of pain differ (28, 29). Therefore, these seemingly discrepant results may reflect the assessment of different pain-related constructs. The cognitive strategies used to assess different pain characteristics is an important area for future research.

We found that when judging pain presence, the most common strategy was to elicit patient self-report. However, the validity and reliability of self-reports for this patient population have not been established. A small study of intensive care unit patients suggested that even when verbal ability was preserved, the rate of symptom reporting decreased during delirium, possibly challenging reliance on self-report (30). Comparable data from the palliative care setting are not currently available. The ability of people with other types of cognitive impairment to verbally self-report pain has received more research attention and debate. For instance, among older people with mild dementia, there is some evidence that training and simplified protocols can lead to reliable self-report (31), but there is also evidence of poor reliability and considerable difficulties with self-report (32). In our study, self-reports were more likely to indicate that patients were in pain than pain-free, consistent with the high prevalence of pain documented in cognitively intact palliative care populations (27). This may indirectly support the validity of these self-reports. However, the prevalence was lower than that detected by behavioral observation. While this may suggest that behavioral observation is more sensitive for this group, it may also reflect poor specificity, in particular the difficulties differentiating pain from symptoms of delirium. Unfortunately, the lack of chart notations describing how self-reports were obtained limits conclusions. The feasibility and psychometric properties of self-report pain scales for cancer patients with delirium remain to be evaluated.

When patients were unable to provide verbal self-reports, HCWs relied on behavioral cues, particularly vocalizations and facial expressions, to judge pain. Although the primacy of vocalizations and facial expressions is consistent with the literature on other patients with impaired ability to report pain verbally (18), the validity and reliability of these cues for this particular group of patients has not been established. This is critical, given the potential for behavioral overlap. For instance, patients may exhibit the same behaviors, such as grimacing and yelling, because of delirium, pain, or both (9). This overlap has important implications for symptom identification and management, including the potential risks of misattribution of symptoms (8, 33). The chart notations were silent on how HCWs disentangled these overlapping behavioral presentations. Prospective research examining the cognitive processes HCWs use to make these important clinical distinctions would provide essential information for the development of a standardized assessment protocol for this population.

An important finding was that despite the lack of such a protocol, HCWs assessed both spontaneous and evoked pain, with the same pain cues (grimacing and moaning/groaning) most commonly described for both. This reflects the well-known distinction between background and incident pain in cancer patients (34, 35). It also suggests that HCWs were taking a proactive, hypothesis-testing approach to pain assessment. It is tempting to conclude that behaviors elicited during a potentially painful experience are due to pain, but the validity of this conclusion can be challenged. It is also possible that the potentially painful experience increases agitation or anxiety, whose behavioral expression is misattributed to pain. Nonetheless, consideration of evoked pain is critical, and an effective, clinically useful assessment protocol for these patients must capture and differentiate these two types of pain.

The development of such a protocol will depend on research focused specifically on pain in older cancer patients with delirium. It is not appropriate to generalize from other cognitively impaired groups because clinical differences between them may impact on behavior in unique ways (26). For instance, acute cognitive dysfunction, advanced cancer, impending death, high symptom burden and polypharmacy, which characterize older palliative care inpatients (36), may impact on pain behaviors in ways that are not comparable to older people with dementia in the long-term care setting. Consistent with this, observational pain scales developed for older people with dementia in the long-term care setting have been shown to perform poorly when used with older people with comorbid dementia and delirium (37). Similarly, pain assessment tools developed for people with delirium in the postoperative (38) or intensive care (39) setting may be limited in applicability. These measures do not consider delirium subtypes and outcomes, the interpretation of nonspecific behavioral cues, or the differentiation of evoked from background pain. Furthermore, it is increasingly recognized that delirium may have different pathophysiology and symptom presentation across patient populations, also limiting generalizations (5, 14, 15). As such, research into cancer pain assessment in older people in the palliative care setting is urgently needed.

Although it is preliminary, this study provides novel information regarding judging pain in this group of patients and is an important first step in the development of a standardized pain assessment protocol. However, the results must be interpreted in light of a number of limitations. Chief among them is that the data are based solely on review of HCWs' chart notations, which may be incomplete or inaccurate (40). We took several steps to maximize the rigour of our chart abstraction, including training data abstractors, using a standardized abstraction protocol, and discussing ambiguous notes or situations (40, 41). Importantly, chart review may have been particularly suitable for our objectives, as it provides rich, naturalistic source data about HCWs' practices in a nonselected sample of patients free of response biases which may operate in the context of a research study (40, 41). In particular, HCWs made their notations without knowledge of their future use in research about pain.

A related limitation is that the study took place in a single, highly specialized, acute palliative care unit with a relatively small sample size, possibly threatening the generalizability of the results. This may be especially relevant to our finding of consistency of pain cues and assessment strategies across delirium subtypes as relatively few cases of hyperactive and mixed delirium were included in the analysis and the diagnosis of delirium was based on clinical interview rather than a standardized measure. However, our findings regarding the prevalence of delirium, its subtypes and outcomes are consistent with larger studies designed to systematically evaluate these issues (2). This supports the representativeness of our sample and increases confidence in our findings. Nonetheless, replication in larger and more diverse clinical settings is welcomed.

The key conclusion from this study is that HCWs routinely made judgments about pain in older patients with delirium using a repertoire of strategies that included patient self-report and observation of spontaneous and evoked behavior. Using these strategies, HCWs judged pain to be highly prevalent in the palliative care inpatient setting. Given these findings, it is critical that research and clinical attention be brought to the careful development of a valid, reliable, and clinically feasible assessment protocol. Improved pain assessment will contribute to enhanced pain management as well as improved quality of life, death and dying in this especially vulnerable group of patients.

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