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### **Exploration of delirium assessment and management in a hospice inpatient unit**

A mixed methods study

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## **TITLE**

**Exploration of delirium assessment and management in a hospice inpatient unit: a mixed methods study.**

## **ABSTRACT**

**Introduction:** Delirium is common across all palliative care settings. Guidelines exist to support the care of terminally ill people who develop delirium; yet the evidence base is limited. Recent surveys of palliative care specialists have suggested clinical practice is variable.

**Objective:** To explore delirium assessment and management in a hospice inpatient setting.

**Methods:** A mixed methods study comprising a retrospective case note review of 21 patients admitted to a hospice inpatient unit and semi-structured interviews with seven hospice inpatient doctors and nurses.

**Results:** Sixty-two percent of patients were screened for delirium on admission using the 4 'A's tool (4AT). The period prevalence of delirium was 76% during the 2-week study period. The term 'delirium' was documented infrequently in case notes, compared to other more ambiguous terms. Interview data suggested that nurses were unfamiliar with delirium screening tools.

**Conclusion:** The lack of awareness about delirium screening tools and the infrequent use of the term 'delirium' suggests delirium may go under-recognised and under-treated. Further education and research are required to support the care of terminally ill people with delirium.

**Words 177**

**Key words:** delirium, palliative, hospice, assessment, management, screening, mixed methods, interviews.

## INTRODUCTION

Delirium is a serious and distressing neuropsychiatric condition<sup>1, 2</sup> which is common across all palliative care settings.<sup>3</sup> The presence of delirium indicates a poor prognosis, with only half of cases being reversible in terminally ill people.<sup>4</sup>

Existing palliative and generic guidance promotes the adoption of delirium screening, including assessment tool use, as earlier detection may lead to improvements in patient outcomes.<sup>5-9</sup> Identification and treatment of reversible causes of delirium is recommended, if 'consistent with the person's goals of care and illness trajectory'.<sup>10</sup> Non-pharmacological strategies are advocated, including reorientation of the person, as well as engaging their family in support.<sup>5-11</sup> The evidence for non-pharmacological management is limited in terminally ill patients, but endorsed due to it being inexpensive and well-tolerated.<sup>10-12</sup> Evidence for pharmacological management of delirium is similarly limited.<sup>12-14</sup> A Cochrane review in 2020 reported low-quality evidence that antipsychotics (haloperidol or risperidone) may slightly worsen delirium severity in mild to moderate cases, compared with placebo.<sup>13</sup> Further evidence is warranted, especially for management of moderate to severe spectrum of delirium. In the absence of high-quality research, palliative care guidelines recommend antipsychotics are reserved for patients with severe agitation, or those at risk of harming themselves or others, and when non-pharmacological measures have failed.<sup>7, 9-11</sup>

In the UK, palliative care is provided to terminally ill people and their families by a variety of health and social care professionals in the community and hospitals. Specialist palliative care services are available to those with more complex needs. Recent surveys have reported the practice of palliative care specialists in delirium screening and management.<sup>15, 16</sup> Despite guidance recommendations, only 5% of specialists reported screening for delirium on admission to units, with 68% screening in response to delirium symptoms. Delirium assessment tools were only used by 37% of palliative care specialists, and there was no consensus about the best tool for this population.<sup>15</sup> Over a third (38%) reported never using delirium guidelines, and there was an awareness of the need for further research to better guide practice, especially regarding management of severe delirium.<sup>16</sup>

## **OBJECTIVES**

The aim of the study was to explore the assessment and management of delirium in patients with terminal illness in a hospice inpatient setting, focussing on delirium screening tools, documentation, and pharmacological management.

## **METHODS**

### **Design**

This was a mixed methods study comprising:

1. A retrospective case note review of patients admitted to a hospice inpatient unit.
2. Semi-structured interviews of hospice inpatient doctors and nurses.

A mixed methods convergent design allowed a combination of quantitative and qualitative data, which provided a more complete understanding of the delirium assessment and management in a hospice inpatient setting.<sup>17</sup>

### **Setting**

This study was conducted at a hospice in Edinburgh, Scotland, which provides inpatient and community adult specialist palliative care services for a population of approximately 500,000. The inpatient unit had a capacity of 24 beds and admitted 407 patients in 2017.

### **Data collection**

#### **Case note review**

A retrospective review of electronic case notes was conducted of patients admitted to the hospice between the 1<sup>st</sup> and 17<sup>th</sup> August 2017. Records were reviewed from the point of admission up to 2 weeks, discharge, or death, depending on which occurred soonest. (This time period was determined by the availability of the researcher CF, a medical student at the time.) For each patient, the following data were collected:

- age, gender, primary diagnosis, reason for admission, and follow-up end point;
- use of delirium assessment tools;
- documentation of a delirium diagnosis and/or any symptom clusters, clinical descriptions, and synonyms suggestive of a delirium diagnosis; and
- information regarding pharmacological management of delirium.

### **Delirium assessment**

Patients were retrospectively assessed as having delirium, based on case note review by a member of the research team (CF). The study's delirium criteria were adapted from the diagnostic delirium criteria in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5)<sup>1</sup> and the 4 'A's test or 4AT.<sup>18</sup> (Table 1)

The 4AT is a short tool for delirium and cognitive assessment, used in clinical practice, at first contact with a patient, or at other times when delirium is suspected.<sup>18</sup> The tool includes four items to score: (1.) level of alertness, (2.) the abbreviated mental test 4 (AMT-4), (3.) a test of attention (reciting the months of the year backwards) and (4.) if there has been evidence of an acute change or fluctuation in the patient's alertness, cognition or other mental function. A 4AT score of 4 or more is suggestive of delirium with/without cognitive impairment.

A high index of suspicion for delirium diagnosis was applied, and ambiguous cases were discussed with a Consultant in Palliative Medicine (JS).

## **Semi-structured interviews**

### **Participant recruitment**

All hospice inpatient nurses and doctors were invited to participate, by internal email and/or direct invitation from the inpatient Nurse manager or Palliative Medicine Consultant.

### **Data Collection**

Three small group semi-structured interviews were conducted in private rooms at the hospice, lasting up to 45 minutes. The audio-recording was kept securely at the study site, then destroyed following transcription. Identifiable information was removed during transcription.

### **Data Analysis**

#### **Case note review**

A visual pathway for each patient was created detailing delirium assessment tool use (including scores), duration of delirium, and the patient's outcome at the end of the 2-week follow-up period.

When analysing delirium documentation in case notes, the relevant excerpts describing delirium were identified, and key words extracted and categorised. Codes were then generated within each category and entered into an online word cloud generator.<sup>19</sup> The size of a code's appearance was reflective of its frequency of occurrence in the case notes.

Data on pharmacological management of delirium was collated, documenting the drug used, dose, route and whether it was administered regularly or 'as required'. Antipsychotics administered for nausea or vomiting were excluded.

### **Group interviews**

The results were analysed using thematic analysis.<sup>20</sup> Verbatim transcripts of interviews were produced and coded using a data-driven approach. The codes were collated into themes (Appendix 1). The respective interview extracts were then grouped into their themes and reviewed manually.

### **Ethical and governance considerations**

The case note review was deemed a service evaluation, and Edinburgh hospice Caldicott Guardian permission received to access patient case notes. Research approval for the interview study was obtained from the University of Edinburgh and hospice Research Governance Group. Participants signed a consent form in advance, and were informed they could withdraw at any time, without consequence.

## **RESULTS**

### **Case note review**

#### **Patient characteristics**

Twenty-one patients were admitted to the hospice over the 17 day-period. Their average age was 71 years (range 50-87 years), with the majority having malignancy as their primary diagnosis (90%). Just over half of patients (52%) had more than one reason necessitating hospice admission – end of life care was the most frequent reason (67%), followed by poorly controlled symptoms (57%). By the end of the study's 2-week follow-up period, 15 patients (71%) had died, 5 patients (24%) were still being cared for at the hospice, and one patient had been discharged home (Figure 1).

### **Delirium screening tool use and delirium prevalence**

Thirteen of the 21 patients (62%) were screened for delirium using the 4AT, on admission to the hospice. (Figure 1) Five of these 13 patients had a 4AT score of 4 or more, suggesting a diagnosis of delirium. A further eleven patients developed delirium over the 2-week study period, according to the study's diagnostic criteria. This suggests the period prevalence of delirium was 76% (16/21 patients) over the 2-week study period. Of these 16 patients with delirium, 81% died within the first 2 weeks of hospice admission (13/16 patients).

### **Delirium description or synonyms**

The term 'delirium' was only documented on eight occasions in the electronic case notes of the 16 patients, assessed as having delirium. 'Agitation', 'confusion', 'distress', 'muddled', 'disorientated' or descriptions of altered consciousness were more commonly used. (Table 2) Figure 2 gives a visual representation of the frequency of delirium descriptors, synonyms and symptoms documented in these patients' case notes.

### **Pharmacological interventions for delirium management**

Pharmacological interventions for delirium management were frequently documented for the 16 patients, assessed as having delirium. Haloperidol, levomepromazine and midazolam were administered regularly for 7, 9 and 10 patients, respectively. However, their indications were often unclear due to multiple interventions being documented simultaneously, in response to individual patient's multiple symptoms. This was particularly the case for the benzodiazepine midazolam, which was often administered to manage symptoms clusters of breathlessness, 'anxiety', 'agitation' and 'distress'.

### **Qualitative results**

Three semi-structured group interviews were undertaken. The participants included four nurses and three doctors (six females and one male). Key themes focused on: (1.) describing delirium; (2.) use of delirium screening tools, (3.) progression from non-pharmacological to pharmacological management, as well as (4.) the role of families.

### **Delirium descriptors**

Participants generally reported being familiar with the term 'delirium', although two nurses were less so.

Nurse 1: 'It's quite an old word delirium, isn't it?'

Nurse 2: 'Delirium wasn't a word I would have normally used. I would have probably used confusion and agitation, as opposed to the word delirium.'

Delirium descriptors given during the interviews included terms 'restlessness', 'aggression', 'vagueness', 'incoherent speech', 'disorientation', 'hallucinations', 'being withdrawn', 'altered consciousness', and 'fluctuating mental state'. The term 'terminal agitation' was used to denote irreversible delirium which develops towards the end of life.

### **Use of delirium screening tools**

Nurses expressed unfamiliarity with delirium screening tools or reported they were only for use by doctors. They were doubtful of their role in diagnosis, favouring the use of clinical judgement and experience over screening tools - examples of patients with rapid onset, severe and/or hyperactive delirium, were given to support their views. Nurses expressed confidence in their ability to recognise and diagnose delirium. It was suggested their longer periods of patient contact resulted in screening tools being less relevant, compared to more intermittent contact by doctors.

Nurse 3: 'The change generally from not being delirious to being delirious tends to be pretty fast, so to apply...a tool to someone who is...wildly confused, I'm not sure has much value.'

Doctors were more familiar with delirium screening tools and spoke positively about the 4AT tool being quick and easy to use. They advocated delirium screening on admission or with ambiguous cases, but were less likely to support its use when the diagnosis or its absence seemed clear from clinical judgement. However, there was recognition the fluctuating course of delirium or presence of the hypoactive subtype could lead to challenges with delirium diagnosis.



Doctor 2: (With regard to using the 4AT)

'Sometimes (patients) can mask it quite well. Then you start asking questions like 'where are you', 'what (is the) date', 'what is your date of birth' and they struggle quite a lot, and then you ask their family 'has this been a recent thing?'

### **Delirium management**

Most participants acknowledged the importance of non-pharmacological strategies, including investigation and treatment of potentially reversible causes. Infection, medication, hypoxia and metabolic disturbance were identified as common triggers in palliative care patients. Yet there was acknowledgment the underlying cause sometimes remained unclear, particularly at the end of life.

Doctor 1: 'Ruling out all the reversible causes... and then I would always go with the kind of environmental stuff before thinking about medicines.'

Non-pharmacological strategies, including reorientation, reassurance, and quiet environments, were described, but some nurses had less confidence in them being effective.

Nurse 3: '(we) try to...verbally reorientate people...but...my personal experience is that it's very temporary or often doesn't really have much of an effect.'

Families were recognised as important sources of support to patients with delirium, but the psychological burden of seeing relatives distressed was acknowledged. There was recognition of families' need for explanation and support.

Nurse 2: 'I remember calling in a family member thinking that might help...at first I thought it was going to work and then it didn't last, and then the family member was... upset and the patient was still not...settling'.

Pharmacological management was advocated for delirium associated with severe distress, to facilitate management of underlying causes of delirium or if there had been a

poor response to non-pharmacological strategies, particularly towards the end of life. Patient safety was also identified as a trigger, including high risk of falls and risk of self-harm. Nurses were more likely to give examples of agitated patients requiring medication at an early stage, whereas doctors focussed more on non-pharmacological strategies initially.

Nurse 1: 'I would rather not go down the pharmaceutical route and I'm sure (Nurse 2) wouldn't either. But sometimes you have no choice because nothing you try works'.

Doctor 1: Depends on how distressed they are. There are some people who just need to... get settled, because they are so distressed that...you actually can't rule out reversible causes because they are too distressed. That becomes a priority'.

Nurse 4: '...if we thought someone was terminally agitated and they were imminently dying, then we would have a low threshold because we want them to be comfortable because they are dying'.

The participants reported the antipsychotics, haloperidol and levomepromazine, as first and second-line medication for managing agitation and distress associated with delirium. It was recognised that benzodiazepines should usually be avoided, as they risked worsening delirium; but could be administered alongside antipsychotics in relieving agitation associated with delirium, or as adjuvants in the management of pain, dyspnoea and anxiety.

Doctor 3: 'A lot of our patients have many symptoms as well, and so actually if you feel there are other symptoms causing the distress like breathlessness or pain, you would be thinking about treating those symptoms where benzodiazepines might be helpful to ease their distress, even though they are not treating the delirium as such'.

Participants commented on the complex decision-making regarding pharmacological management of delirium in palliative patients. Patients' goals of care and their disease trajectory were considered relevant. Recognition of delirium at the end of life was also

recognised as challenging. Seeking advice or consensus with colleagues was reported as helpful.

Doctor 3: 'I guess the key...is how much investigation is appropriate and what's our management strategy depending on where the patient is on their journey with the trajectory.'

Doctor 3: (Regarding agitated delirium towards to end of life) I think...there is a grey area...that only...becomes clear with time if it's...related to the very terminal phase.

## **DISCUSSION**

Delirium was common amongst the hospice inpatients and associated with a poor prognosis in this study. The prevalence figures are consistent with a recent systematic review, which estimated the median point prevalence of delirium on admission to palliative inpatient settings as 32% (range 6.6%-73%) and a period prevalence prior to death as 75% (range 58%-88%).<sup>3</sup>

Guidelines recommend delirium screening and use of assessment tools, on admission to new care settings, and subsequently when delirium is suspected.<sup>5-9</sup> However, assessment tool use was suboptimal in this study, with the 4AT being omitted on admission for 38% of patients. Hospice staff expressed confidence in their clinical judgement to detect delirium, although it was acknowledged the hypoactive subtype may be more challenging to diagnose. Nurses were unfamiliar with delirium assessment tools or considered their use the doctors' responsibility. This likely reflects hospice practice at the time of the study. Similarly, a UK survey in 2019 reported only a third of palliative medicine specialists used screening tools, with more preferring to use their clinical judgement alone.<sup>15</sup> Yet it is increasingly recognised that clinical judgement alone risks delirium going under-diagnosed and untreated.<sup>16, 21</sup>

The case notes review revealed the word 'delirium' was documented infrequently. Descriptive terms such as 'agitation', 'confusion', 'muddled', 'disorientated' and descriptions of level of consciousness were used more commonly. Ambiguous terminology and shortfalls in assessment tool use have been reported as potentially compromising patient care, in other research.<sup>22, 23</sup> A review of delirium documentation in

patients' case notes, in a hospital palliative care setting, suggested that patients with a definite delirium diagnosis had clearer management plans, compared to those with 'less definite, descriptive alternative terms'.<sup>23</sup> Agar *et al.* (2020) also suggested the use of non-specific delirium terms, including 'terminal agitation' and 'terminal restlessness' may compromise quality patient care, particularly towards the end of life.<sup>24</sup>

All participants acknowledged the importance of identifying and treating potentially reversible causes of delirium. Some nurses had low expectations of non-pharmacological strategies, which may have been due to their propensity to use examples of severe delirium. Conversely, non-pharmacological measures have been perceived as valuable in other palliative care settings.<sup>25</sup>

Specific triggers for pharmacological management were identified as severe distress or agitation, especially when unresponsive to non-pharmacological strategies, which is consistent with delirium guidelines and other research.<sup>5-12</sup> A high mortality rate was detected among the patients identified to have delirium in this study, with 81% dying within 2 weeks of being admitted to the hospice. This, together with the frequency of medication use, suggests patients were experiencing moderate to severe delirium, associated with agitation or distress towards the end of life; although midazolam may have also been indicated for other symptoms, including anxiety or breathlessness.

Strengths of the study include the mixed methodology, allowing documented and self-reported practice to be compared, and inclusion of both hospice doctors and nurses. Limitations were the case note review was completed retrospectively, and delirium judgements were made by a student researcher, according to a subjective appraisal of criteria for delirium diagnosis. The interviews consisted of a small sample of staff participants based at a single hospice, which limits their subsequent generalisability to other healthcare professionals and hospice settings. The data was collected in 2017, and informed an increase in delirium awareness and training locally. This, in conjunction with an improved international focus on delirium, may mean the results are unrepresentative of current practice.

## **Future research**

Given the small scale nature of the present study, re-running this prospectively, using a larger sample, collected across multiple sites, would update and enhance generalisability of findings. Further research is required to inform delirium guidelines and clinical practice. The 4AT is used in palliative care settings, yet validation studies are required to confirm its reliability in this patient population.<sup>15, 21, 26</sup> Such studies are underway.<sup>27</sup> Research into delirium documentation and its management in *real time* would be beneficial, as this would permit the chronological study of non-pharmacological and pharmacological measures. Research into how healthcare professionals' understanding of delirium affects their management choices, would also be valuable. Implementation studies would examine how delirium screening could be better embedded into clinical practice. As many terminally ill people are cared for in their homes and care homes, similar delirium studies are also needed in these settings.

### **Implications for practice**

The findings from this study support previous research highlighting the prevalence of delirium as end-of-life approaches.<sup>3</sup> Despite this, one-third of patients were not screened for delirium *on admission* to the hospice unit, in this study's sample. Given the prevalence of delirium, we recommend that routine screening forms part of the patient admission process. Furthermore, patients were judged to have developed delirium *during* their hospice admission. This replicates previous findings and highlights the need for delirium assessment beyond first admission. Brief assessment tools, such as the 4AT, can be easily administered, to support clinical judgement, in detecting delirium. Earlier detection permits more timely management, which may improve patient outcomes.

Further education and training of both medical and nursing staff are required to develop expertise in delirium assessment and management. Clearer documentation and communication concerning the diagnosis of delirium is also warranted. The term 'delirium' should be used when the condition is suspected (as opposed to synonyms), as this may lead to improved patient care and support for their families.

### **CONTINUING PROFESSIONAL DEVELOPMENT: Reflective questions.**

1. Consider the challenges of recognising delirium in people with terminal illness?
2. Consider non-pharmacological approaches in delirium prevention and management?

3. Consider how families of terminally ill people, who develop delirium, can be supported?

## **SUPPLEMENTARY INFORMATION**

### **Authors' contributions**

AF and JS devised the study protocol, and supervised the primary researcher (CF), a 5<sup>th</sup> year medical student at the time of data collection. All authors contributed to the data analysis, discussion, and manuscript preparation.

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**Competing interests** - None

**Availability of data and materials** - Further information is available from the corresponding author.

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