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Identifying the barriers and enablers to palliative care nurses' recognition and assessment of delirium symptoms: A qualitative study

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Delirium recognition and assessment

Title: Identifying the barriers and enablers to palliative care nurses' recognition and assessment of delirium symptoms: a qualitative study

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[22, 23] - leading to inconsistent delivery of appropriate interventions to delirious patients.

Delirium under-recognition is linked to a range of factors, such as clinician delirium knowledge gaps [24-26] existing alongside the complexity of delirium phenomenology: widely differing presentations, with fluctuating symptoms and ranging degrees of severity and manifestations of change to cognitive and psychomotor activity [27, 28]. The predominance of the hypoactive sub-type of delirium in palliative care inpatient settings – with its quiet, lethargic presentation easily mistaken for other common problems in this population, namely fatigue or depression [22, 28, 29] - and the need for development of evidence for effective and feasible delirium screening, assessment and treatment approaches in this unwell, frail and dying patient population [30, 31] also contribute to the problem of under-recognition.

Delirium under-recognition does not align with the World Health Organisation definition of palliative care, that champions the need for impeccable assessment and preventative action to optimise patient-centred care and relief of suffering at the end of life [32]. Regardless of whether or not delirium is preventable or reversible for the individual patient, optimal person and family centred palliative care is best achieved through this accepted approach to the problems associated with a life limiting illness. Developing the evidence for more effective strategies for delirium recognition, assessment and treatment is becoming increasingly recognised as a priority within palliative care practice development and research agendas. [30, 31]

The need to build palliative care nurses' capacity to recognise and assess delirium
Palliative care nurses have a key role in delirium care due to their intimate patient contact over the 24-hour period and a professional obligation to apply a systematic,

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context of inpatient palliative care and their delirium recognition and assessment practice, including what limits and supports this practice.

Aim

The aim of this study was to identify nurses' perceptions of barriers and enablers to recognition and assessment of delirium symptoms within specialist palliative care inpatient settings.

Method

Use of the critical incident technique

Our study was guided by the critical incident technique (CIT). This research method collects and analyses data related to participants' clearly recalled memories of a specific incident, to determine effective, ineffective and missing practices, as well as factors or characteristics that help, hinder or are critical to an activity. [45, 46] This paper reports on data specifically relating to participants' perceptions of barriers and enablers to delirium recognition and assessment in palliative care inpatient settings. As participant recruitment, data collection and researcher reflexivity have been previously described in detail, [35] a brief overview only of study methods is provided here.

Participants

Registered or enrolled nurses [47] working in Australian specialist palliative care inpatient settings, with at least 12 months clinical experience and more than three months palliative care experience, were eligible to participate in this study.

Setting

In Australia, specialist palliative care inpatient units are commonly situated as stand-alone wards within acute or sub-acute hospitals and employ multi-disciplinary teams to provide symptom management, respite and terminal care for patients with life-

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and interviews continued for until no new information was being obtained and data saturation was apparent. [52]

Data analysis

Interviews were transcribed verbatim. Data analysis was an inductive process using thematic content analysis. [52] Transcripts and field notes were read and re-read, promoting immersion in the data [AH]. Data were entered into an electronic spreadsheet with interview questions providing an initial frame of reference for the multiple codes generated by the data. From this open coding [AH, with independent coding of three random transcripts each by JP, EL], data relating to participant perceptions of barriers and enablers of nurse recognition and assessment of delirium symptoms were examined closely and categories of patient and family, health professional and system levels identified. Preliminary themes were generated [AH, JP] and then discussed by the researcher team [AH, JP, EL, MA, PD]. Collaborative analysis and verification continued until final themes were established, that aim to reflect participants' perceptions of barriers and enablers to nurse recognition and assessment of delirium symptoms in inpatient palliative care settings. [52] The 'COREQ: consolidated criteria for reporting qualitative research' guided reporting of this qualitative data. [53]

Results

Thirty nurses from 9 specialist palliative care inpatient services across three Australian states participated (Table 2). Twenty-five face-to-face and five telephone interviews averaging 21 minutes duration (range 7-62) were conducted in late 2012 - early 2013. Despite participants' varying capacity to recall and recount specific delirium incidents, all were familiar with the challenges of nursing palliative care patients experiencing delirium symptoms and provided insights into delirium

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1) Barriers and enablers at the patient and family level

Value in listening to patients and engaging families

Participants acknowledged the challenges inherent in recognising and assessing

delirium: *"It's a very difficult symptom, or condition, to diagnose and then treat..."*

(P16) Participants believed patients were often reluctant to report their symptoms, due to embarrassment or fear of being seen as 'crazy'. Another perceived barrier was the use of cognitive assessment processes requiring lengthy quiz like questioning of patients, such as those routinely employed in Australian inpatient settings, [54] as these were perceived to be too burdensome for palliative care patients who were frequently frail and fatigued:

“ “What date is it? Where are you? Do you know this? What year? Who's the prime minister?” ... Let's be a little bit more gentle and understanding when we're trying to pick up any sort of confusion in patients... fatigue is a big factor for our patients, where they just don't have the energy any more to do a lot of the things that we ask them, or to answer the questions...” (P16)

It was suggested that the challenge of recognising and assessing delirium could be better addressed if nurses communicated caringly with patients, to establish rapport and trust. Even though this process also involved questioning of the patient, the questions instead centred on patient comfort:

“Just communicating with her a little bit more, finding out why she's awake. “Is there anything more we can do? Is something worrying you? Are you uncomfortable?” All those basic things, talking to her, just sitting for a few minutes in the middle of the night beside the bed and just holding her hand.” (P13)

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Participants identified that barriers to recognising and assessing delirium at the patient level were challenges inherent to the complexity of delirium, patients' reluctance to report troubling changes to their cognition and perceived burden of cognitive assessments requiring lengthy questioning. Enabling factors included establishment of trust and rapport between patients and team members through verbal and non-verbal communication of caring and active engagement of family members in the patient assessment process.

2) Barriers and enablers at the health professional level

Assessment is integrated with care delivery

Participants identified time and workload pressures as a barrier to delirium recognition and assessment: "*Because, no way, you don't (have) an hour or two of your day to try and find out what is going on.*" (P01). Yet despite time and workload pressures, participants strived to focus their attention on individual patients during care delivery. This participant believed that it was in making an explicit decision to focus, listen and talk with patients during physical care delivery - rather than be distracted by the many nursing 'tasks' needing completion - that they came to a better understanding of what was happening for the individual:

"You can give a patient a shower in a relaxed, peaceful manner, taking time to have a conversation with them, or you could be like a mad woman and try and do two showers at once and one wash, and be thinking about the next thing ...and the patient's talking to you and you're not listening..." (P04)

Personal contact and interaction with the patient enabled participants to identify changes and conduct both ongoing and continuous assessment:

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structured delirium ‘tool’; instead they proceeded to report any concerns to either a more senior nurse or the doctor.

Respecting and integrating nurses’ observations

Perhaps because of this absence of a structured, explicit delirium assessment, some participants indicated that other team members - particularly doctors and other nurses - did not always appear to respect their clinical observations. This in turn appeared to restrain participants from feeling confident and effective in their delirium recognition and assessment role:

“We communicate...what’s happening with the patients...you make suggestions to doctors or you bring it to their attention...(but) I think the doctors could be a little more respectful of the value of the nurses’ information and then nurses more respectful of (our) own opinions” (P04)

Whereas *“if everyone can work as a team”* (P13) this enabled participants’ initial reporting of delirium symptoms and they believed this led to further multi-disciplinary assessment and improved patient outcomes. Deliberate and conscious efforts to engage with medical colleagues were made to support teamwork, rapport and mutual respect:

“We’ve just got a new resident and registrar at the moment so it takes a little bit of time to build a rapport, that they can see, “Oh look these (nurses), they’re pretty good” ... then you’re all aiming for the same thing with the patient. Saying hello to them in the morning, “Hi, good morning, how was your weekend?” Not just all walking past each other.” (P13)

There were examples where relaying observations to the doctor and being listened to resulted in resolution of patients’ delirium:

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cognition were a barrier to recognition and assessment of patients' delirium; conversely when participants perceived that they were respected and listened to by others in the team and had regular opportunities to report their observations, this enabled more timely and effective multidisciplinary responses to patients' delirium symptoms. However, team strategies specifically designed to identify delirium were not described.

Addressing nurses' delirium knowledge needs

Participants acknowledged that nurses' delirium knowledge gap was a major barrier to delirium recognition and assessment: "*I just think as nurses we are not trained enough in dealing with delirium*" (P03); and "*I think it's an area where we haven't really even begun to ...understand - that's probably what I've learnt about delirium!*" (P09) Even though having cared for many patients with delirium, several participants acknowledged their own delirium knowledge deficits:

"Assessment is usually crucial, but it's just knowing how to assess... I don't know what the questions would be." (P01)

They also acknowledged that beliefs that a patient's personality or old age explained delirium behaviour was a barrier to prompt recognition: "Don't just think: "*It's old age*" (P07) and:

"How do you get you know a person to change their thinking from "That's a batty old lady" to "Oh, well there might be something else going on there...?" (P19)

This participant highlighted how her lack of knowledge about the potential for steroid medication to precipitate delirium resulted in feelings of bewilderment about a patient's agitated behaviour and delays in recognition of his delirium:

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like: Where was that? Where did we miss it? What was the first trigger?"

(P09)

This theme highlights that participants readily acknowledged delirium knowledge deficits, erroneous beliefs and limited education opportunities within nursing practice as barriers to optimal delirium recognition and assessment; while they believed their practice could be enabled through development and local delivery of delirium education, particularly using debriefing and 'real-life' patient scenario learning approaches.

3) Barriers and enablers at the system level

Integrating delirium recognition and assessment processes

Translation of delirium evidence into palliative care nurses' routine practice might also be regarded as a system level factor. For example, despite comprehensive delirium assessment in frail, unwell and elderly patients being a complex, multi-faceted process and the availability of numerous delirium clinical practice guidelines [2, 3, 17] very few participants reported ready access to delirium protocols, guidelines or integrated systems that translated this delirium knowledge into their workplace – in fact, many identified their absence:

“Unfortunately the (admission) assessment doesn't ask about delirium or depression...and it's not a daily thing that we screen.” (P09)

In the few settings where delirium guidelines were embedded within the hospital as a whole, participants described the value of these documents, for both their own practice and when delivering delirium education to other nurses within their workplace:

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workplaces. [39-41] Addressing each of these barriers is required to optimise palliative nurses' delirium practice. But less frequently reported in the literature have been nurses' delirium practice strengths and/or factors they believe support them to contribute to effective delirium management. [57] Our study identifies a number of perceived practice enablers and opportunities to strengthen nursing engagement in early recognition and comprehensive assessment of delirium in palliative care settings. These included: establishment of trust and rapport with the patient; actively obtaining the insights of family; integrating assessment into direct patient care; working within a collaborative, respectful and dynamic team environment; and potential benefit of integrating delirium education and routine, systematic processes at the local level.

Our findings related to inter-personal interactions are important, because these remind us of the primacy of positive, caring relationships with others in the provision of person-centred and compassionate end of life care, be it with patients, family members or our colleagues. [17] Patients and family members similarly value care that demonstrates respect, sensitivity and maintenance of dignity during an episode of delirium, [7, 58, 59] which ought inform the way we conduct delirium assessment. However, effective recognition and assessment of delirium cannot be achieved solely through clinicians' bedside interactions with patients - however compassionate or present - nor respectful team relationships generally, as these qualities alone do not provide the explicit, honed focus required to distinguish delirium, [60, 61] particularly when the overall complexity of palliative care patients' symptom management and holistic care needs is considered. As structured team conversations have positively impacted upon other outcomes for palliative care patients, [62] there is great potential benefit in building multidisciplinary team members' delirium knowledge, [63]

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observation and assessment role and processes for effective team communication, tailored to the specific requirements of each speciality or setting of care.

It is encouraging that nurses in this study believed adoption of delirium guidance tools in their workplaces would improve practice and patient care outcomes, as this reflects recommendations within all current delirium clinical practice guidelines. [2, 3, 17] Numerous delirium tools exist, such as risk assessments, [3, 67, 68] screening and assessment tools, [69] clinical pathways [70] and algorithms. [71] Although observational delirium screening tools are not yet extensively developed, tested or implemented in palliative care settings, [4, 72] there is emerging evidence that their routine use by nurses in palliative care inpatient settings is effective and feasible. Rao et al (2011) reported that palliative care nurses successfully integrated screening into their daily practice using an observational and shortened version of the Confusion Assessment Method (CAM) [73, 74], while Gagnon et al (2012) reported successful implementation of the Confusion Rating Scale (CRS) [75] by bedside nurses in seven palliative care units/hospices during a three-year delirium prevention trial. [76] Of note, a full CAM was applied in only 39% of participants in the later study, due to patients' impaired consciousness or perceived burden of the structured interview, [76] highlighting limitations of the full CAM version in palliative care settings. Most recently, Detroyer et al (2013) applied the Delirium Observational Screening Scale (DOSS) [77] in a palliative care unit, reporting good diagnostic validity and nurse perception that the tool was user friendly; however, it relies on patients being able to communicate verbally, limiting its applicability across the whole of this inpatient population. [78]

Informed by these prior studies and views of nurses who participated in our study, implementation of structured delirium recognition and assessment processes into

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Strengths and limitations

While perceptions of Australian palliative care nurses in various roles, workplaces and geographical locations are captured in this study, nurses self-selected to participate in this study, so a limitation is that these participants' views may represent those most interested in delirium. Almost all participants were female and while likely to be generally representative of the gender of Australian nurses, is another limitation of the sample. Most aspects of this study were guided by the CIT, yet for data inclusion we deliberately choose to include all participants' insights relating to delirium recognition and assessment barriers and enablers, consistent with the overall intention of CIT to reveal factors that help or hinder an activity. [45, 46] Adopting this approach provides valuable insight into nurses' views on barriers and enablers to their current and future delirium practice, with the caveat that these qualitative findings may not be transferable to other regions and settings of care. Participants were not directly asked to describe barriers and enablers to their delirium recognition and assessment practice, which potentially limits the completeness of our findings. Including the voices of participants through use of verbatim quotes and independent coding of six random transcripts by two additional coders during data analysis strengthens the reporting and analytic rigor of our study. [52]

Conclusion

The findings of this study reveal that palliative care nurses are striving to provide effective, person-centred and compassionate care to patients experiencing delirium symptoms, but that they are doing so with limited delirium knowledge and educational opportunities and in the absence of structured screening, assessment and team processes. These nurses also identified how their delirium practice might best be developed. Given the prevalence of delirium experienced by palliative care patients, addressing the multi-level factors that impact on palliative care nurses' ability to

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Table 1

Delirium scenario

Mrs X is admitted to your palliative care unit on Monday. She is widowed, aged 81, lives alone and her diagnosis is advanced lung cancer. The reason for admission is for symptom management, as she has escalating pain. She has a son and daughter, but she is unaccompanied by any family or friends at admission. Medical and nursing admission processes are completed. Mrs X was independent with ADLs prior to admission. She shares a four-bed room with 3 other female patients.

Her opioid and adjuvant doses are increased after admission and by day 3 her pain appears to be improving.

Mrs X is a quiet, cooperative lady who displays no signs of agitation, but is noted to be a little vague in her verbal responses. She interacts only occasionally with the other patients in the room. She sleeps for intervals during the day, and is sometimes slow to rouse. Night staff report that she is awake for periods of time each night. When awake, she sits quietly and watches what is happening in the room.

Her son visits her each evening after he finishes work. On the evening of the fourth day of admission, he speaks to the nurse on duty and tells her that his mother has told him that she can see a dead man in the corner of the room, and that it has been there since she arrived on the ward. He also reports that his mother is not as clear in her speech and thinking as is usual for her.

The nurse speaks to Mrs X about this. Mrs X says she has been wondering why no one has talked about this man and that she was too frightened to report what she was seeing, in case people thought she was 'crazy'. She reveals that she finds the sight of the dead man very disturbing, and is worried she is 'losing her marbles'. She also reports she is finding it harder to concentrate and remember simple things.

Table 2

Table 2: Characteristics of the sample (n=30)	
Characteristic	Number
Gender	
Female	29
Male	1
Age	
21-30	3
31-40	11
41-50	9
51-60	6
61-70	1
Position Title	
Registered Nurse	16
Clinical Nurse Specialist	6
Enrolled Nurse	2
Clinical Nurse Consultant	2
Nursing Unit Manager	2
Clinical Nurse Educator	1
Nurse Practitioner Candidate	1
Highest qualification	
Certificate	5
Diploma	4
Bachelor	9
Post graduate certificate	9
Post graduate diploma	7
Type of palliative care inpatient service	
Direct care, mixed unit	17
Direct care, palliative care patients only	10
Consultative	3
Geographical location of workplace ★	
Major city	28
Inner regional	1
Outer regional	1
Remote	1
Years of nursing experience	
1-3 years	2
3-5 years	5
6-10 years	2
11-15 years	6
16-20 years	5
> 21 years	10
Years of palliative care experience	
< 1 year	1
1-3 years	5
3-5 years	4
6-10 years	9
11-15 years	8
16-20 years	1
> 21 years	2

★ Totals more than 30 because one participant worked in more than one geographical area