

Improving the Management of Terminal Delirium at the End of Life

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ABSTRACT

Objective: Terminal delirium is a distressing process that occurs in the dying phase, often misdiagnosed and undertreated. A hospital developed the “comfort measures order set” for dying patients receiving comfort care in the final 72 h of life. A chart review of patients experiencing terminal delirium revealed that the current medication option initially included in the order set was suboptimally effective and patients with terminal delirium were consistently undertreated. The purpose of this pilot study was to highlight an in-service intervention educating nurses on the management of terminal delirium at the end of life and to assess its effect on their knowledge of the management of patients with terminal delirium. **Methods:** A before-and-after survey design was used to assess the effect of the in-service training on nurses' knowledge of terminal delirium. **Results:** We describe the results from a small

sample of nurses at a large urban tertiary care center in Canada. Of the twenty nurses who attended the in-services, 60% had cared for a patient with terminal delirium; however, 50% felt that their knowledge of the topic was inadequate. Despite no statistical significance between the pre- and posttest scores for both the oncology and the medicine unit nurses, all participants who completed posttest survey found the in-services useful. **Conclusions:** The findings from this study provide initial insights into the importance of in-service trainings to improve the end-of-life care and nursing practice. Future research will include expanding this pilot project with sufficient power to assess the significance of these types of interventions.

Key words: End of life, imminently dying, knowledge translation, order set, terminal delirium

Introduction

Terminal delirium occurs in the last hours and days of life,^[1] often as a result of end-stage organ failure and other irreversible factors.^[2] The prevalence of terminal delirium has been reported as high as 88% in actively dying patients.^[1] Terminal delirium is distressing for patients,^[3,4] their family members, as well as health-care providers.^[5,6] Terminal delirium can be challenging to diagnose; hence, it is frequently overlooked and undertreated.^[6]

Delirium is classified into three types: hyperactive delirium characterized by agitation, aggression, and hallucinations; hypoactive delirium characterized by somnolence; and mixed delirium characterized by features from both subtypes.^[2,7-9] Other signs include moaning, facial grimacing, fluctuating level of consciousness, incoherent speech, changes in sleeping patterns, erratic emotions, confusion, and disorganized activity.^[7,10,11] It is

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well-documented that clinicians receive limited educational training in identifying patients who are imminently dying and in managing the end-of-life care.^[12,13] Nurses are the primary decision-makers for the administration and titration of symptom management medication and the implementation of appropriate nonpharmacological interventions to provide relief from the end-of-life symptoms and to support patients' families. Therefore, it is recommended that health-care providers have access to educational opportunities focused on the care of patients at the end of life^[14,15] to better familiarize bedside nurses with the assessment, etiology, and interventions of terminal delirium.

The implementation of standardized order sets has been demonstrated to help identify gaps in the health-care provider's knowledge and practices and to improve patient care. A major university-affiliated hospital in Toronto, Ontario, launched the comfort measures order set (CMOS) for imminently dying patients targeting patients with a prognosis of fewer than 72 h and a documented preference for comfort-oriented care.^[16] Common end-of-life symptoms addressed by the CMOS include pain, dyspnea, upper airway secretions, and terminal delirium. The initial CMOS included haloperidol as the only pharmacological option for the management of terminal delirium in addition to nonpharmacological interventions for health-care providers to consider.

In 2018, Lau *et al.* published results from their review of the care received by patients on the CMOS. The study revealed that patients on the CMOS had fewer medication adjustments as compared to those without the CMOS. However, dyspnea and terminal delirium were the two most frequently identified symptoms causing distress at the end of life. Subsequently, a chart review was conducted of those 41 patients previously identified as having terminal delirium in that study.^[16] Findings from this review highlighted that despite the CMOS, palliative care physicians made frequent medication changes to manage terminal delirium in more than 90% of the patients. In addition, nursing staff did not administer the prescribed "as needed" antipsychotic medications to over one-third of the patients, and 10% of the patients were physically restrained at some point in the last 72 h of life.^[17] These findings emphasize that a high proportion of actively dying patients with terminal delirium are undertreated even with CMOS initiated.

Therefore, the objective of this study was to implement and evaluate an educational in-service to ensure that nurses have the skills, knowledge, and attitude necessary to provide care to patients experiencing terminal delirium.

Methods

A quantitative design was utilized to evaluate the in-service training program. A before-and-after survey was used to assess the effect of the intervention on nurses' knowledge of the management of patients with terminal delirium. Ethics approval was obtained from the appropriate institutional Research Ethics Board.

Setting and recruitment

The study took place from January 2019 to May 2019. Convenience sampling was used to recruit nurses for the in-services. Flyers were posted on the nursing communication boards on each of the respective units a few weeks prior to the in-service to alert the staff of the study. On the day of the in-service, an announcement was made at the beginning of the shift to remind the staff of the in-service scheduled. In-services were conducted on the hospital's general internal medicine and oncology units, as a previous study demonstrated that these units generate the highest volume of referrals for end-of-life care.^[18] Nurses were asked to complete a baseline survey and a follow-up survey after the in-service training.

Intervention

A total of four in-services were held; these were staggered and covered a 12-h shift (day – evening shift and evening – night shift). Two in-services each were conducted on the medical and the oncology units. The in-services were 30 min each in length and were taught solely by the author (MS). In-services were kept short so that recruitment was high, as both the units are busy and nurses have multiple competing demands on any given shift.

The in-service began with a 10-min didactic PowerPoint presentation which included the definition of terminal delirium, types of delirium, pharmacological and nonpharmacological management strategies, and factors that can contribute to terminal delirium. A case study was embedded into the in-service, followed by interactive questions to stimulation, reflection, and illustrate applicability to practice [Appendix A]. The discussion portion of the in-service was not tape recorded as the in-service was time specific. The case study and pre-and postsurvey questions were reviewed by the nurse educator on the oncology unit to ensure that these captured the acuity the nurses' experience on the unit.

Survey

To evaluate the effectiveness of the in-service, participants were asked to complete the same questionnaire pre- and post-in-service [Appendix B]. The survey collected demographic information and also comprised five close-ended questions to evaluate knowledge of terminal

delirium. The survey was developed by the researchers and was reviewed by each of the nurse educators on the oncology and general internal medicine unit for feedback prior to its utilization.

Data collection and evaluation

Nursing demographic data were collected from participants prior to the session. The surveys pre and post were administered in paper format. Pre-post scores were derived to assess the effect of in-services quantitatively [Figure 1a and b]. Each correct response was assigned with a score of 1 and an incorrect response with a score of 0. Questions left blank in the tests were marked as incorrect. The final pre- and post-scores were then calculated by adding participants' scores for each response. If a participant responded to all five questions correctly, they would receive a score of 5. People who did not attempt their posttest surveys were omitted from further analysis.

Statistical analysis

The nurses' demographic characteristics were summarized using descriptive statistics. Inferential analyses of the in-services included Wilcoxon signed-rank test and Wilcoxon–Mann–Whiney U-test using SAS 9.4 (SAS Institute Inc., Cary, NC, USA.). These nonparametric analytic approaches were chosen to account for the violation of normality assumption caused by the very small sample size in our analysis. The significance threshold was set at 0.05.

Results

The sample consisted of 20 English-speaking nurses employed at the hospital: 13 in oncology (36% of the total

nurses employed on the unit) and 7 in medicine (21% of the total number of nurses employed on the unit). All 20 participants were female. The majority of the oncology nurses were between 36 and 55 years of age (54%), compared to the majority of medicine nurses who were between 20 and 35 years of age (57%) [Table 1]. More than half of the nurses across both the groups had between 0 and 10 years' experience (55%). The highest level of education was seen to be quite different across the two groups. The majority of oncology nurses had a master's education (77%), while more than half of the nurses for the medicine group had an undergraduate degree (66%) and far fewer had a master's degree (33%). All participants in the medicine unit were employed full time, while one participant in the oncology unit was casually employed. All participants had cared for an imminently dying patient with the CMOS. In the oncology group, 62% had cared for an imminently dying patient experiencing terminal delirium; similarly, in the medicine unit, 57% had cared for such a patient. When asked if they felt competent to care for a dying patient with terminal delirium, 54% of oncology nurses answered "yes," 15% answered "no," and 31% were unsure. In the medicine group, 42% felt competent and 57% were unsure.

Question two "The CMOS currently uses Lorazepam to pharmacologically treat terminal delirium (True or False)" was the most common incorrect pretest answer across both groups (40%). A Wilcoxon signed-rank test revealed no statistically significant difference between the pre- and posttest scores for both the groups, ($n = 10$, $Z = 10.5$, $P = 0.1094$ for oncology unit nurses) and ($n = 7$, $Z = 5$, $P = 0.1250$ for medicine unit nurses).

We also performed a Wilcoxon Mann–Whiney U-test to assess whether the posttest scores differed between the oncology and the medicine unit nurses. The analysis exhibited no significant difference in the posttest scores between the two groups of nurses, $P = 0.6029$ for a two-sided test.

Despite no statistically significant difference in the nurses' knowledge of the management of terminal delirium pre- and post-in-services, the survey results revealed that all participants who took the posttest survey found the in-services helpful in improving their knowledge of this topic.

Discussion

Delirium is a common symptom experienced by palliative care patients in their final days or weeks of life. The management of terminal delirium can present a challenge to health-care providers, as the use of antipsychotics must be balanced against patients' and families' desire to maintain

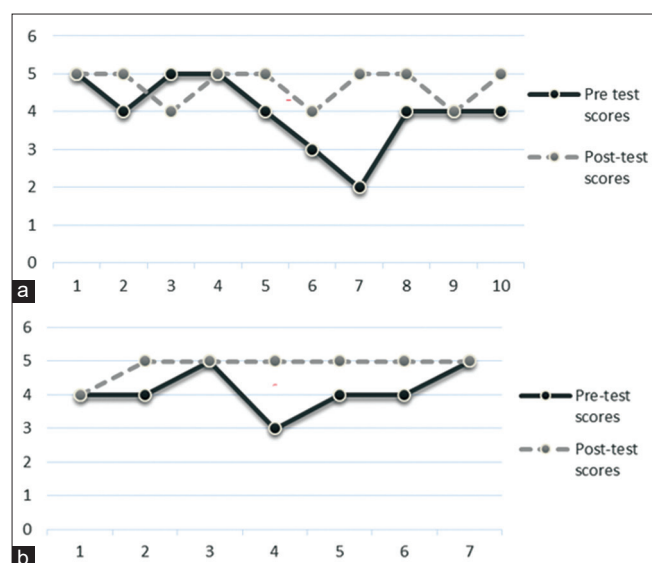


Figure 1: (a) Oncology nurses pre- and posttest scores. (b) Medicine nurses pre- and posttest scores

Table 1: Participant characteristics

Characteristics	Frequency (%)		
	Oncology nurses	Medicine nurses	Overall
Age range, years	<i>n</i> = 13	<i>n</i> = 7	<i>n</i> = 20
20-35	5 (38.46)	4 (57.14)	9 (45.00)
36-55	7 (53.84)	3 (42.86)	10 (50.00)
56 and above	1 (7.69)	0 (0.00)	1 (5.00)
Years as a RN or RPN	<i>n</i> = 13	<i>n</i> = 7	<i>n</i> = 20
0-10	7 (53.84)	4 (57.14)	11 (55.00)
11-20	3 (23.07)	1 (14.29)	4 (20.00)
21-30	3 (23.07)	2 (28.57)	5 (25.00)
Highest level of education	<i>n</i> = 13	<i>n</i> = 6	<i>n</i> = 19
College	2 (15.38)	0 (0.00)	2 (10.53)
Undergraduate	1 (7.69)	4 (66.67)	5 (26.32)
Master's	10 (76.92)	2 (33.33)	12 (63.16)
Have you ever cared for an imminently dying patient with the CMOS?	<i>n</i> = 13	<i>n</i> = 7	<i>n</i> = 20
Yes	13 (100.00)	7 (100.00)	20 (100.00)
Have you ever cared for an imminently dying patient experiencing terminal delirium?	<i>n</i> = 13	<i>n</i> = 7	<i>n</i> = 20
Yes	8 (61.54)	4 (57.14)	12 (60.00)
No	2 (15.38)	2 (28.57)	4 (20.00)
Unsure	3 (23.08)	1 (14.29)	4 (20.00)
Do you feel competent to care for an imminently dying patient?	<i>n</i> = 13	<i>n</i> = 7	<i>n</i> = 20
Yes	7 (53.85)	3 (42.86)	10 (50.00)
No	2 (15.38)	0 (0.00)	2 (10.00)
Unsure	4 (30.77)	4 (57.14)	8 (40.00)

CMOS: Comfort measures order set; RN: Registered nurse; RPN: Registered practical nurse

cognitive clarity as much as possible at the end of life. While the introduction of a standardized order set has been proven as an effective way to help manage dying patients' symptoms, we noted insufficient administration of "as needed" medications by nursing staff for the management of terminal delirium even when a standardized order set was introduced at our institution. We recognized this as an opportunity to better educate our hospital's nursing staff around the optimal management of terminal delirium through an educational in-service intervention.

Over half of the nurses in this project had cared for a patient experiencing terminal delirium, emphasizing the common prevalence of this symptom at the end of life. All nurses had used the CMOS, although 40% were unaware of the current medication option to manage terminal delirium as per the existing CMOS, and 50% felt incompetent or unsure of how to care for a patient experiencing terminal delirium. This may be in part due to difficulties in the detection of terminal delirium, which relies on health-care providers' expertise.^[19-21] The ambiguous nature of terminal delirium and lack of universal delirium screening tools in palliative care can create a sense of uncertainty among health-care providers when identifying terminal delirium.^[5] Synonymous terms such as terminal agitation and widely held misconceptions about terminal delirium also contribute to confusion around its identification and management (for example, the falsely held belief that an

agitated terminal delirium is an inevitable part of the dying process or misconstruing symptoms of terminal delirium as an expression of pain by dying patients).^[4,7,14,20,22]

In-services have the potential to improve care and practice in contexts in which end-of-life care is provided, and we hypothesized that our in-service would advance the knowledge of our nurses in recognizing and managing terminal delirium. While our findings did not suggest a statistically significant difference in nurses' terminal delirium knowledge following the in-service, all participants who completed the posttest reported their perception that the in-service was useful in improving their knowledge. This encouraging finding suggests increased comfort among acute-care nurses following the in-service. Moving forward, more in-depth educational interventions combined with standardized tools for the recognition and diagnosis of terminal delirium will be useful in improving nurses' knowledge and optimizing end-of-life care for patients.

Our patients were located exclusively in an acute-care setting where task-oriented, curative care is prioritized over palliative care. This is in contrast to nurses working in a palliative care setting where the environment is less "task-focused" and more conducive to nursing presence with their patients, allowing for the time to detect cognitive changes and to better understand the patients' experience. Educational interventions such as ours is the first step toward a greater culture change in acute care that will allow

nurses to recognize the distressing end-of-life symptoms earlier and focus on delivering patient-centered end-of-life care.

Limitations

This project took place on two acute-care units and yielded a small sample size. The sample size could be attributed to unit acuity and workload of the nurses. Other studies that tested an educational intervention about symptom distress with end-of-life delirium found that knowledge and competence increased post intervention.^[23] Since our study is limited by a small sample size, it does not have sufficient power to draw a reliable conclusion. In addition, the short duration of the in-service due to time constraints may have limited the knowledge translation opportunity for the nursing staff, thereby impacting their post-in-service results.

Next steps

Moving forward, the advanced practice nurse from the palliative care team will continue to provide ongoing education to capture all general internal medicine and oncology nurses and also plans to emphasize this symptom in the hospital's oncology unit orientation for new staff. Long-term impact and sustainability are recognized as imperative for ongoing quality improvement but are beyond this project time frame. Future research will include expanding this pilot project with sufficient power to assess the significance of these types of interventions.

Conclusion

The findings from this study provide initial insights into the importance of in-service trainings to improve nursing practice and end-of-life care. The CMOS has already prompted positive improvements in the quality of care delivered to patients dying in acute care at our organization; however, improving end-of-life care is an iterative process. Organizations must ensure that nurses utilizing end-of-life order sets are familiar with the assessment and management of symptoms experienced by dying patients including terminal delirium, and educational in-services are one method to attain this goal.

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Nil.

Conflicts of interest

There are no conflicts of interest.

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Appendixes

Appendix A: Case study embedded within the in-service

Mr. H is 79 years old admitted to Sunnybrook hospital after his wife found him on the floor of their upstairs bathroom. Mr. H was recently diagnosed with metastatic pancreatic cancer. He declined chemotherapy but agreed to have a biliary drain inserted 3 weeks ago and since then has been declining functionally, eating poorly, and requiring more pain medication. The care team had a family meeting, and the goals of care have shifted from cure to comfort measures. Over the course of the next day, Mr. H becomes increasingly withdrawn with periods of incoherent speech, moaning, and attempting to climb out of bed despite reassurance and reorientation.

1. What kind of terminal delirium is Mr. H experiencing mild to moderate or severe?
2. What are some other factors that could be contributing to the terminal delirium?

Appendix B: Demographic, pretest, and posttest questionnaire

Please circle answers

Age range

20–25 26–35 36–45 46–55 56–65 65+

Gender

Male or Female

License

Registered nurse Registered practical nurse

Years as a registered nurse or registered practical nurse

0–5 6–10 11–15 16–20 21–25 26–30 30+

Years as a nurse in current care setting

0–5 6–10 11–15 16–20 21–25 26–30 30+

Highest level of education

College Undergraduate Degree Master's Degree PhD

Work status

Casual Part-time Full-time

Hours in a typical work week

0–12 13–24 25–36 37–48 48+

Are you currently employed anywhere else as a nurse?

Yes No

If yes, what type of care setting?

Long-term care Palliative care Oncology Critical care Other (specify): _____

Have you ever cared for an imminently dying patient on the comfort measure order set?

Yes No Unsure

Have you ever cared for an imminently dying patient experiencing terminal delirium?

Yes No Unsure

Do you feel *competent* to care for an imminently dying patient with terminal delirium?

Yes No Unsure

Please answer the following questions by circling your answer.

1. Terminal delirium occurs in the last hours and days of life.
True False
2. The comfort measures order set currently uses Lorazepam to pharmacologically treat terminal delirium.
True False
3. Which of the following is/are non-pharmacological treatment strategies to manage terminal delirium?
 - i. Dim lighting
 - ii. Reassuring voice
 - iii. Music therapy
 - iv. Hand holding
 - v. All of the above
 - vi. None of the above
4. Physical restraints should be used to manage an imminently dying patient with terminal delirium.
True False
5. What is/are other contributing factors to consider and rule out when a patient at end of life is terminally delirious?
 - i. Bowel impaction
 - ii. Urinary retention
 - iii. Pain
 - iv. Sleep deprivation
 - v. Unresolved family issues
 - vi. All of the above
 - vii. None of the above

Did you find this in-service useful?

Yes No

Please provide feedback below:
