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When We Document End-of-Life Care, Words Still Matter



To the Editor:

In the September 2018 edition of the *Journal of Pain and Symptom Management*, the study “Language used by health care professionals to describe dying at an acute care hospital” focused on specific word choices when documenting end-of-life care.¹ They accurately note that, in acute care settings, the patient’s medical record often becomes the primary mechanism for communication between providers. Imprecise documentation can lead to poor transfer of knowledge and even implicit bias.² Wentlandt et al. describe the “implied state” category as most frequently used by nonpalliative care providers, which labels patients by the care they receive (e.g., “he receives comfort care”) without clearly indicating estimated prognosis. Specific terms such as “dying,” “die,” and “passing” (a word that many would characterize as an inexact euphemism) were only documented 24.7% of the time.

Words still matter. Provider discomfort compassionately employing clear, direct terms (e.g., “your father is dying”) has been well described.^{3,4} The unintended consequences of using oblique terminology (e.g., “your father is transitioning”) certainly include miscommunication (“you mean my father has been moved to a different room?”) and missed or delayed opportunities to engage in the grieving process. What this study underlines is the remarkable extent to which provider discomfort talking about death and dying extends away from the patient/family encounter to the clinical chart: we are anxious to say these things even to each other.

We applaud the efforts of Dr. Wentlandt and colleagues to shine the light onto our communication practices within the medical record. Perhaps, these findings offer the opportunity for our own hospice and palliative care field to clearly define best communication practices. For example, the *Journal of the American Geriatrics Society* recently took a stance on language by requiring its authors to use the term “older adult” when referring to someone aged 65 years or older

rather than seniors or elderly.⁵ We suggest *JPSM*, and other discipline-specific journals consider adopting similar word choice policies related to terminology of death and dying—let’s set a standard for others to follow.

Sincerely,

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Response to Hyoscine Butylbromide for the Management of Death Rattle: Sooner Rather Than Later



Dear Editor:

I read the recent paper regarding death rattle treatment with great interest.¹ The authors are commended for giving consideration to this naturally occurring patient noise that is distressing to clinicians and families.

Clinicians have largely believed there is no patient distress as death rattle develops in the context of declining consciousness. We established that there is no patient distress associated with the development

of death rattle in the last days. A prospective, two-group observation study was conducted; patients who were near death were stratified into those with and without death rattle. The patients were observed, and death rattle and respiratory distress were simultaneously measured. There were no differences when patients with and without death rattle were compared.²

Two systematic reviews revealed that no medications or nonmedication treatments are superior to a placebo.^{3,4} Furthermore, attempts to remove the secretions with suction resulted in patient discomfort.⁵

Thus, it remains clinically counterproductive to prescribe medications with limited or no effectiveness in the face of no patient distress. Although Mercadante's team found promise to the proactive administration of hyoscine butylbromide, this medication must be administered parenterally perhaps contributing to patient discomfort. Perhaps, our efforts should be directed to assuaging family members' and clinicians' distress at hearing death rattle, which does not entail medicating the patient, by normalizing the sounds of death rattle for those who hear it.⁶

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Author's Response



To the Editor:

The intriguing questions raised by Campbell deserve several comments:

1. Campbell et al.'s study¹ was cited to suggest that patients with death rattle (DR) do not exhibit distress, and it is true that, intuitively, one could argue that a patient with a significant reduction in the level of consciousness may not feel distress (who knows?). However, the study also shows an association between the entity of the DR and an objective (i.e., not reported by the patient) measure of respiratory distress (RDOS), which has been used in patients with different levels of consciousness. In patients who were capable of responding (22%), a correlation between RDOS and some objective measures (SO₂ and need for oxygen, but not hypercarbia), and intensity of dyspnea, was observed. The RDOS score was higher in patients with cognitive impairment or who were dying.² These data show the complexity of this situation.
2. It is important to consider the reason that studies have failed to find advantages with anticholinergics.³ As described in the discussion of our trial, there is no drug able to remove what is already formed. The pragmatic study we performed was based on the observation of patients who are traditionally treated with drugs after DR occurs (like those reported in literature) and patients receiving the drug once the level of consciousness decreases to the point that protective reflexes are inefficient before the development of DR. Considering that DR will develop in a large number of patients, a preventative treatment could represent a new way to use old drugs, which were ineffective if used in a wrong way. Of interest, a large study was planned to confirm the observation reported in our study.⁴
3. We are aware of a retrospective report on the patient discomfort with suction of secretions,⁵ but the outcome depends on how one proceeds. In a patient with a low level of consciousness, a small bolus of propofol or midazolam (if it is already used for palliative sedation), may avoid any discomfort for patient, even with laryngoscopy, and the risks of mucosal damage are minimal.⁶ We agree that it will depend on the experience of the operator who performs the procedure, but at the same time, we think that skilled personnel should be available in any place where palliative care is provided.