

The Death Rattle Dilemma

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Death rattle, defined as the noise created by the flow of air through secretions in the upper respiratory tract, is a well-known phenomenon associated with the dying process. The use of anticholinergics is standard practice in hospice and palliative care, yet despite a growing number of quality clinical trials, there is still no compelling scientific evidence that our interventions for death rattle are effective. Studies to date have focused on antisecretory agents, primarily anticholinergics, with mixed results and variable interpretations. Recent placebo-controlled data suggest that death rattle may tend to diminish over time without medication. Objective measurements of patient distress indicate that dying patients experience very low levels of respiratory distress with or without death rattle. While treatment is often initiated based on the perceived distress of family members, emerging qualitative data suggest that death rattle is not always distressing to family and caregivers. Our current approach to death rattle presents a clinical and ethical dilemma; a better understanding of the range of responses and interpretations will allow nurses to frame the discussion of death rattle more effectively and help to guide care. More research is needed into nonpharmacologic, particularly communication-based, interventions for death rattle.

KEYWORDS

anticholinergic, communication, death rattle, dying, symptom management

Case Study

Mr E. was 66 years old with advanced gastric lymphoma and was dying at home, being cared for by his family. He was somnolent, but his respirations were unlabored, and lung sounds were clear. The hospice nurse

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educated his family on the signs and symptoms of active dying and the use of comfort medications, including 1% atropine eye drops to be given sublingually as needed for respiratory secretions.

SIGNIFICANCE

Alternately referred to in the literature as terminal congestion, retained secretions, noisy breathing, and respiratory tract secretions, death rattle is well known as a phenomenon associated with the dying process. Although the term death rattle may seem macabre, it is a pragmatic expression for a common occurrence at end of life and has the advantage of being both descriptive and widely recognizable. The varied terminology reflects a divergent body of research, the cumulative results of which have yet to define a criterion standard of treatment. This is due in part not only to inconsistent terminology, but also to the variable quality and conflicting findings between studies. Despite barriers to research in dying patients, there is growing evidence to suggest a lack of utility of our treatments for death rattle.²⁻⁶ This is especially important in light of research indicating that treatment is often given to alleviate the distress of family and caregivers, including health care professionals, while those who hear it are not always distressed by the sound.^{7,8} In fact, objective measures indicate low levels of respiratory distress in dying patients and no difference in distress between those with and without death rattle. This article provides an overview of both the historical evidence and more recent developments and offers a new perspective on this old symptom that can inform our approach to the care of the dying as well as families and caregivers. The role of nurses in incorporating this new knowledge into practice is key. Nurses are in every setting where patients receive care, often as the clinicians most intimately involved in the care of dying patients. As such, nurses are most likely to be caught in the clinical and ethical dilemma presented by death rattle. They are also in a unique position to help manage symptoms and address suffering at end of life while expanding our knowledge and understanding of the needs of patients and families.

BACKGROUND

Death rattle is commonly defined as the noise produced by the oscillatory movement of upper airway secretions with the inspiratory and expiratory phases of respiration.⁹ Different authors have proposed various mechanisms for the development of death rattle but tend to agree that



the accumulation of upper respiratory tract secretions in the oropharynx and bronchi secondary to a loss of cough and swallow reflexes as well as possible increased activity of M2 and M3 muscarinic acetylcholine receptors leads to partial airway obstruction. The flow of air through these secretions is thought to produce the death rattle, which in turn is affected by ventilatory rate and airway resistance; a lack of adequate expiratory airflow increases airway resistance, thus increasing the intensity of the noise. While this proposed mechanism is plausible, it is important to recognize that the pathophysiology of death rattle is hypothetical and has been neither directly studied nor demonstrated through research.

Historically, death rattle has held a close popular association with impending death, ¹ and current research largely supports this connection. It has been found to be a strong predictor of imminent death, with 76% of subjects in 1 study dying within 48 hours of onset. ⁹ Reported prevalence varies widely; a range of 12% to 92% reflects a lack of large, prospective trials, differences in methodology and definitions, and the challenge of objective measurement of death rattle. ^{4,5}

A standardized assessment tool, the Death Rattle Intensity Scale, ¹¹ has been used in a few studies with some minor variations. ^{2,12,13} While the tool has face validity, no published validity or reliability data are available to support its use. The Victoria Respiratory Congestion Scale (Figure 1) offers a similar system for rating the intensity of death rattle. ¹⁴

The current standard of care for individuals who develop death rattle includes nonpharmacological measures such as those listed in Figure 2. Their effectiveness, however, has not been studied, and interventions such as suctioning may cause discomfort. A,6,15 One recent study found no relationship between parenteral fluids and development of death rattle, although guidelines still recommend reducing fluids. Pharmacological interventions are routinely used: palliative care texts invariably advocate the off-label use of anticholinergic medications for the treatment of death rattle. Research on these pharmacological interventions is more robust but still fails to provide compelling evidence for effective treatment that changes the natural history of the clinical presentation. Data are now emerging to suggest



Victoria Respiratory Congestion Scale (VRCS)

VRCS Score	Observation
0	Congestion absent
1	Congestion audible at 12 inches(30 cm) from patient's chest but not further
2	Congestion audible at the end of the bed but not further
3	Congestion audible at the doorway of the room

Instructions:

- The staff member stands beside the patient's bed, bends slightly over the patient's chest, turns his or her head at 12 inches(30 cm) from the chest, and listens for several breaths. The staff then moves to the end of the bed and listens again for several breaths, and similarly at the door of the room
 - ♦ If no congestion is heard at the chest, the score is 0/3
 - ♦ If congestion is heard at the chest but not the foot of the bed, the score is 1/3
 - If congestion is heard at the chest and at the foot of the bed only, the score is 2/3
 - ♦ If congestion is heard at the doorway, the score is 3/3
- Distinction should be made between 'congested breathing' and 'snoring' or 'tachypnea' which are not counted as congestion
- Room noise should be reduced as possible (e.g. radio or television turned down) during assessment
- The room size is based on an approximate single room. If in a larger four-bed ward, the distance from the bed to where an average doorway would be is used
- Whatever the room size or ambience, repeated measurements should replicate as best as possible the same conditions in order to compare changes in the VRCS

Victoria Respiratory Congestion Scale (VRCS). Medical Care of the Dying, 4th ed.; p. 384. © Victoria Hospice Society 2006.

FIGURE 1. Victoria Respiratory Congestion Scale (VRCS). Reprinted with permission.



- Gentle oral suctioning^{10, 17, 20, 25, 33}
- Side-lying or semi-prone position^{10, 17, 20, 25, 30, 33}
- 1-2 minutes in lateral Trendelenburg position to mobilize secretions to oropharynx for suctioning³³
- Education for patients, families and caregivers^{1, 2, 6, 13, 20}

FIGURE 2. Nonpharmacological interventions for death rattle.

that commonly used anticholinergic medications may all be equally ineffective in treating death rattle. ^{2,4,13,19}

PHYSIOLOGY AND PHARMACOLOGY

The use of anticholinergics for death rattle is predicated on the mediating role of the muscarinic receptors. 1,20-22 These receptors regulate fluid and electrolyte secretions from enterocytes as well as the secretion of saliva. 21 Receptor dysfunction due to factors such as infection can lead to hyperreactivity with resulting bronchoconstriction and increased secretions. The antisecretory effects of anticholinergics are due to their competitive antagonism of muscarinic receptors; this is largely supported by data from the field of anesthesiology, where they are used to protect against vagal reflexes and to reduce oropharyngeal secretions during surgery. Commonly used drugs in this class include hyoscine hydrobromide, atropine, and its precursor hyoscyamine, which are classified as tertiary amines, and hyoscine butylbromide and glycopyrronium bromide or glycopyrrolate, both quaternary amines. Tertiary amines are smaller molecules easily absorbed across membranes such as the intestinal wall and blood-brain barrier, whereas the larger quaternary amines are not. Those that cross the brain-blood barrier can cause adverse central effects such as sedation, confusion, and paradoxical agitation. Peripheral adverse effects in both groups can include dry mouth, bradycardia, tachycardia, dysrhythmias, and urinary retention. 21 The pharmacokinetics of these drugs in dying patients is not well defined.

Some researchers have attempted to differentiate between death rattle that does or does not respond to medication by noting an association between refractory symptoms and pathological respiratory processes such as lung metastases and infection. ^{9,10} A recent retrospective analysis, however,

failed to support this association, although there was a significant association with higher anticholinergic load prior to entering the dying phase and the later use of anticholinergics for death rattle. This may be due to up-regulation of the muscarinic receptors from previous use of medications with anticholinergic properties such as opioids, corticosteroids, and antiemetics or a cholinergic rebound effect caused by discontinuation of oral medications at the end of life. Figure 3 outlines other potential causative factors in the pathophysiology of death rattle, underscoring the complex, multifactorial nature of the symptom as well as the challenge inherent in attempting to treat it.

CURRENT EVIDENCE

Clinical trials conducted to date have focused on antisecretory agents in the treatment of death rattle, primarily anticholinergics, with mixed results and variable interpretations. Given the unknown natural history of death rattle, there are unfortunately few placebo-controlled studies. One recent randomized trial compared sublingual atropine to placebo (n = 137). Differences in reduction of death rattle were not statistically significant. In fact, after an interim analysis for superiority and futility, the study was stopped because of lack of difference between groups. Noise scores in both groups tended to improve over time, perhaps giving some indication of the natural course of death rattle. The only previous randomized, placebo-controlled study compared hyoscine hydrobromide to saline (n = 31). The authors found a tendency toward decreased death rattle in the hyoscine group.

Several studies on the management of death rattle report similar outcomes, with no significant difference seen between agents; whereas some authors interpret this as an indication of the lack of efficacy of these drugs, others interpret it as an indication of equal effectiveness. The largest randomized

- Excessive salivary production relative to the ability to swallow^{1, 9, 10, 30}
- Respiratory weakness secondary to neuromuscular disorders, loss of airway reflexes^{1, 10, 20}
- Excessive bronchial secretions secondary to tumor or infection^{1,9}
- Reactive changes in bronchial epithelium^{1, 10}
- Pulmonary edema secondary to cardiac dysfunction¹
- Pulmonary edema secondary to thalamic hypoxia¹
- Opioid use may contribute to reduced level of consciousness, respiratory rate and cough reflex¹⁰

FIGURE 3. Proposed causative factors in secretion production and retention.



trial to date (n = 333) compared the effectiveness of 3 commonly used anticholinergics. ¹² There was no significant difference in the effectiveness of atropine (42%), hyoscine butylbromide (42%), and scopolamine (37%) for treating death rattle at 1 hour (P = .72); more than half of the participants in each arm had no response. The authors conclude that the 3 agents are equally effective in the treatment of death rattle. In a pilot phase II study comparing octreotide and hyoscine hydrobromide, 11 of the subjects either died prior to receiving treatment or their secretions subsided spontaneously. ³ Of the remaining 10 patients, 9 had no response to the first dose of medication. The authors conclude that no clinically meaningful efficacy was shown in either arm.

In contrast to these negative studies, 2 trials reported positive findings. One small randomized controlled trial (n = 13) found glycopyrrolate to be significantly more effective compared with scopolamine. 24 A retrospective study of 22 patients found 68% responded to sublingual atropine with a reduction or resolution of death rattle. 22 The authors reflect that other possible contributing factors, such as the tendency toward mouth breathing in dying patients, may have led to drying of oral secretions. Even given these positive studies, it seems clear that the evidence for treatment of death rattle with anticholinergics is limited at best. In fact, there appears to be growing support for the view that these medications may not have a role in the care of the dying patient. $^{2-6}$

Case Study Continued

Over the course of several hours, Mr E. developed noisy, rattling breathing. The family called hospice and were instructed to give 2 drops of atropine. An hour later when the nurse called back to check in, his family reported Mr E.'s breathing was increasingly noisy and more labored. She then arranged to make a home visit for further assessment.

IMPACT ON FAMILIES AND CAREGIVERS

There is wide consensus in the literature that the sound of death rattle is distressing to families and health care professionals. ^{15,17,25} The impact of death rattle on families and caregivers, especially the suggestion that families are disturbed by the sound, is of central importance to this discussion for 2 reasons: treatment is often initiated based on the perceived distress of family members, ^{1,18,25} and perhaps most significantly, there is as yet no compelling scientific evidence that our interventions for death rattle are effective. ^{1,6,19,26} This presents an ethical dilemma in that using these drugs involves giving potentially ineffective treatment to an individual who is likely unconscious and unable to give consent or report adverse effects, and treatment may be initiated based on the emotional and psychological distress of the cli-

nician or family member. ⁶ It also presents a clinical dilemma in which the natural course of the symptom is unknown, and the most appropriate intervention has yet to be determined.

Available qualitative data bring into question the perception that death rattle is universally distressing to family. Two studies were conducted using a qualitative, interpretive approach with bereaved relatives. 7.8 In the first study (n = 12), 5 interviewees expressed negative feelings about hearing death rattle, whereas another 5 indicated that they were not distressed by the sound. One participant expressed regret that her husband did not develop it because otherwise she would have stayed with him on what turned out to be his last night of life. In the second study, 10 of the participants were distressed by the sound, whereas the remaining 7 found the sound reassuring or viewed it as a useful sign of imminent death. These findings offer the first direct evidence to support the idea that some family members are distressed by the sound of death rattle, but also refute the assumption that all family members experience distress. The participants in these studies reacted to and interpreted the sound of death rattle in a variety of ways, suggesting that administering medications on the basis of presumed distress will sometimes be less than beneficial.

The tension between the desire to alleviate perceived suffering and uncertainty about our ability to do so is highlighted in a qualitative study of the impact of death rattle on hospice staff and volunteers.²⁷ The study also explored why and how physicians and nurses decide to intervene. Most participants reported negative responses to the sound of death rattle using terms such as "scary" and "disturbing," although some were less affected, basing their response on the relative comfort of the patient. Many also commented on their concern regarding the negative effect of the sound on family members and other patients. Both doctors and nurses expressed a sense of obligation to provide treatment for death rattle, at the same time acknowledging that these interventions are not always effective. Some provided treatment as a comfort to the family; doctors indicated that their decision to prescribe medication was often based on requests from nurses or family. Nurses recognized the role their own emotions played in the decision to administer medication. Two recently published qualitative studies with health care professionals found similar themes, affirming the difficult clinical and ethical dilemma in which practitioners find themselves when dealing with death rattle. 28,29

In contrast to the actual and perceived impact on family and caregivers, the effect of death rattle on the patient is generally thought to be relatively benign. ^{10,18} A recent study, the first to attempt to objectively quantify patients' response, found very low levels of respiratory distress in dying patients and no difference in distress between those with and without death rattle. ² Some have questioned the role of treatment if patients are unaware of the symptom. ²⁸ Yet there may be a potential for physical and psychological morbidity in



family members who witness this or other symptoms that could be equated with a "bad death." Given the uncertainty surrounding the effectiveness of pharmacological interventions and the presumed suffering of family members, the literature on death rattle frequently emphasizes the importance of communication. This presumed distress may have more to do with the impending loss of a loved one than the sound of death rattle itself; if so, then the role of communication in addressing potential suffering takes on even greater importance. Sensitive communication and time simply spent with family members are likely to be the most effective intervention for death rattle. 1,3,28

Case Study Conclusion

When the hospice nurse arrived, Mr E. appeared uncomfortable, and the family was anxious. His daughter stated, "I feel like I failed him by not giving the medication soon enough." The nurse explained that death rattle is likely not uncomfortable and that response to medication is variable. She did note increased work of breathing and administered a bolus dose of morphine through his patient-controlled analgesia pump, instructing the family in the use of morphine for dyspnea. With repeated boluses, Mr E.'s respirations grew easier. He died later that evening with his family at his side.

IMPLICATIONS FOR PRACTICE

Theories of etiology and approaches to treatment of death rattle continue to evolve in the palliative care literature. Taken as a whole, the available data highlight clinical and ethical dilemmas that should give us reason to reexamine our approach to death rattle. In addition to equivocal evidence for the effectiveness of medication, it would appear that, in treating death rattle, medication is often provided not for the benefit of the patient but for those who hear and are affected by the sound. Indeed, new data indicate that patients with death rattle do not experience respiratory distress.² The dilemma of death rattle, however, is not simply whether medications are effective or whether those who hear it experience distress. Offering medication for death rattle may set family and caregivers up for failure, possibly creating a sense of moral distress. A lack of consideration of possible adverse effects seems to reflect an assumption that these effects are an acceptable risk in dying patients.³¹ Most importantly, the focus on drugs to the exclusion of investigation into nonpharmacological interventions would appear to reflect a degree of medicalization in the palliative approach; in addressing only the symptom of death rattle and not its larger meaning, the medication becomes our response to dying.³² The current literature represents a shift to a broader perspective and more holistic approach, but there is more work to be done.

The response that families and caregivers may have at hearing death rattle is likely inextricable from a complex affective response to the impending death. It is both a universal and a deeply personal experience, with responses potentially falling across a wide range of emotions and interpretations. The extent to which health care providers are able to normalize death rattle as an expected part of the dying process may also influence their own attitudes and those of family and caregivers. 4,15 The modifying effect of anticipatory preparation and education on these groups is largely unknown and warrants investigation; the interventions listed in Figure 2 present another area for research. In the absence of evidence for effective treatment and a basic lack of understanding of the natural history of death rattle, communication and attention to the potential suffering of patients and families must be the primary focus of our interventions. A better understanding of this response allows health care providers to frame the discussion of death rattle more effectively and perhaps reduce or eliminate pharmacological interventions implemented solely to relieve the perceived distress of family members.

In addition to providing compassionate care to the dying and their families, nurses are poised to carry out research to fill gaps in the evidence base and generate rich data to expand our understanding of this phenomenon. As we build on our knowledge of death rattle through rigorous qualitative and quantitative research, studies looking at pharmacological and nonpharmacological interventions, including the provision of support and education, will provide key data to guide safe, ethical, and effective care.

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