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Death Rattle: reassuring harbinger of imminent death or a perfect example of inadequacies in evidence-based practice.

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"Nothing in life is promised except death"
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Abstract

Purpose of Review

Death is the inevitable consequence of life. Although clinicians are unlikely to accurately pinpoint when death is likely to occur in the people they care for, the death in a person with a diagnosis of malignant and non-malignant tends to involve a period of predictable progressive clinical and functional deterioration. During this time, it is common for death rattle to occur. Due to its presentation, death rattle can cause stress and distress to caregivers. This often prompts clinicians to consider medical interventions that are not only ineffective in treating the problem but may also do harm.

Recent Findings

There is a dearth of research related to the management of death rattle.

This paper discusses the existing evidence in the management of death rattle, considerations for clinicians in the absence of reliable evidence and suggests areas for future research.

Keywords

Death rattle, palliative, dying, evidence based practice, symptom relief, drug therapy

INTRODUCTION

It does not require a great, or indeed wise, philosopher to observe that the one life event we shall all eventually experience is that of dying. Furthermore, as health and social care has progressed, people are inevitably living longer with increasing co-morbidities, complex symptom clusters and expectations of the healthcare system. Whilst sudden death is often difficult to predict, it is usually a mercifully brief process lacking a sustained agonal symptom burden. However, most deaths associated with progressive malignant and non-malignant disease are preceded by a period of clinical and functional deterioration, allowing opportunity to prepare for death on a psychological, social and biophysical level. This may include legacy work (1, 2), making financial/ legal arrangements and is a time for advance planning to ensure appropriate management of end of life care.

One of the commonest signs associated with the dying process is what is colloquially known as a *death rattle*; noisy and abnormal breathing arising from increased or retained bronchial and/or pharyngeal secretions. With a prevalence as high as 92% (3), death rattle is so common that we may have become almost ambivalent to its presence. A Cochrane review focusing on interventions for death rattle, originally undertaken in 2007 has recently been re reviewed and not required any further updates. The review concluded that there is no evidence that any intervention, pharmacological or nonpharmacological, was superior to placebo in the treatment of noisy breathing in dying people (4)

When faced with death rattle, despite no evidence to the efficacy of any pharmacological intervention and little evidence related to the distress that death rattle causes the dying person(5), healthcare and medical professionals often blithely administer antimuscarinic drugs. Concurrently and ritualistically, families are also told that their loved ones are experiencing no distress from the noisy breathing. In the absence of reliable evidence, it is easier for some to respond to a clinical sign, or distressed relative with a pro re nata 'as needed' medicine than invoke the greatest tool in our armoury; person communication and reassurance.

CURRENT APPROACHES TO DEATH RATTLE MANAGEMENT

Although this may not always be the case, evidence from international studies indicates that audible death rattle can magnify some family member's distress, not least because they equate the noise with pain, suffering, drowning and suffocating(6-9). Additionally, they may perceive that care is less than optimal and, in their bereavement, consider that a 'bad' death ensued. This, in turn, may contribute to a poor end of life care experience and even impact negatively on bereavement. Yet, audible death rattle is also a powerful symbol that heralds the imminence of enduring separation. Confronting the reality of this can be difficult and unbearably painful. It is possible that this, rather than the audible death rattle, may be the root cause of people's distress.

Reporting findings from their prospective, two-group observation study of people ($n=71$) approaching death with and without death rattle in North American palliative care and hospice settings, Campbell and Yarandi(10) concluded that there was no correlation between the intensity of death rattle and respiratory distress. Yet, we still do not know with any degree of certainty if death rattle generates distress in imminently dying people. Nevertheless, if these people do appear distressed by death rattle, existing guidance in the United Kingdom (UK) and developed countries beyond, recommends pharmacological and concomitant non-pharmacological interventions (11-13). However, the range of interventions to ease death rattle is limited and their efficacy ambiguous.

The recommended pharmacological interventions from which healthcare professionals might consider, involve administering and monitoring the effect of antimuscarinic agents such as hyoscine hydrobromide (hyoscine), hyoscine butylbromide (buscopan), glycopyrronium bromide and atropine. Yet, there is a sense that such guidance is rather curious. This is because the body of existing empirical evidence for the pharmacological management of established death rattle is still small and characterised by a dearth of robust, high quality studies(14). In other words, weak or no evidence. An important point to consider is that attempts to research death rattle have primarily been focused on the context of advanced cancer. Furthermore,

a definitive trial of antimuscarinic drugs has not yet been achieved. In part, this is because of the difficulties and sensitivities of recruitment at the very end of life. Nevertheless, what is clear is that in the presence of death rattle, antimuscarinic drugs are not always effective in easing the secretions and the noise and could be harmful.

While antimuscarinic agents may not have an effect on existing secretions, they may decrease the production of new secretions(15). Greater appreciation of antimuscarinic agents' mechanisms of action has inspired recent investigations of the effectiveness of their prophylactic administration to prevent death rattle occurring (16, 17). In an Italian study, Mercandante *et al.*(16) trialled the effects of hyoscine butylbromide (buscopan) in dying people with reduced consciousness when given prophylactically compared with its administration once death rattle had begun. This was a two-arm randomised trial. With caregivers' consent, 132 people with consciousness score of < -3 using the Richmond Agitation Sedation Scale – palliative version (RASS-PAL)(16) and considered to be dying imminently were randomly assigned to one of two groups. Those allocated to group one ($n=81$) were given the standard treatment of hyoscine butylbromide once death rattle started ($n=49$). Those allocated to group two ($n=51$) were administered hyoscine butylbromide prophylactically. Once treatment had been initiated all participants were assessed by a nurse at predefined intervals, namely: 30 minutes, one hour and then every six hours until death. The intensity of death rattle was assessed using the Death Rattle Intensity Scale (DRIS)(18). Treatment was considered effective when death rattle intensity was assessed as either being 0 or 1 or if there was a minimum of one-point improvement in the DRIS score. Treatment was considered ineffective if the DRIS score was 2 or 3, or if there was no change in intensity.

The results indicated that death rattle occurred in 60.5% ($n=49$) of participants in group one and 5.9% ($n=3$) in group two. Treatment eased death rattle in just 20.4% of participants ($n=10$) in group one and the median onset of death rattle was longer in group two (36 hours as compared with 12 hours). The authors concluded that prophylactic use of hyoscine butylbromide in people approaching the very end of life

and with reduced consciousness may be effective in preventing the onset of death rattle.

Nevertheless, this prospective study is not without limitations. It is a relatively small study without a placebo arm and conducted with people who have advanced cancer in hospice settings. Whilst recognising that not all participants in the standard treatment arm developed death rattle (39.6%) the prophylactic use of an antimuscarinic heralds an important development in the empirical investigation of treatment efficacy for death rattle not least because the strength of the signal, that is to say the research conclusions, may reduce the importance of the noise (design imperfections)(19, 20).

van Esch *et al.*(17) are yet to report findings from their randomised double-blind, placebo-controlled, multi-centre trial assessing the effectiveness of prophylactically administered subcutaneous scopolamine butyl in preventing the onset of death rattle. Their protocol paper indicates a robust methodology in terms of engaging gatekeepers in the research design together with the use of standard operating procedures. This, together with current, focused interest in the identification of risk factors may predict the development of death rattle(14, 21). Furthermore, it indicates that there is interest in, and support for the investigation of prophylactic pharmacological interventions for death rattle.

Nevertheless, we also know that anti-muscarinic medication can do harm. Current evidence suggests that there may be undesired side effects, such as dry mouth, blurred vision and urinary retention(22, 23). Administering medication to a dying person without sound rationale and that may cause harm to appease the potential stress and distress of caregivers poses a significant ethical and legal dilemma for clinicians. Brighton and Bristowe{Brighton, 2016 #28} suggest that clinicians can avoid creating situations where unnecessary or potentially harmful interventions are considered by having anticipatory discussions with caregivers. Death rattle is a common consideration in end of life care. Therefore, clinicians should prepare

caregivers and manage their expectations about the role of medical interventions, as is done routinely in other areas of end of life care, for example food and fluid intake.

Recent evidence from studies in the UK and beyond signifies a pressing need to enhance death rattle care. Findings from a cross-sectional survey undertaken in Japan with bereaved family members ($n=181$) of people who had died of cancer showed that 53% of participants reported a need for improvement in death rattle care(10). More recently, suboptimal management of death rattle has been revealed in a qualitative analysis of data derived from the UK Palliative and end-of-life care Priority Setting Partnership (PeolcPSP) survey(24), and findings from a qualitative investigation of bereaved relatives experiences of end of life care in the acute stroke care setting(25). Nevertheless, questions surround the therapeutic benefits of antimuscarinics given their potential for adverse effects, for example dry mouth, constipation, urinary retention and sedation. Moreover, these are effects which, like death rattle itself, if experienced, unconscious people are unable to report.

Non-pharmacological interventions are part of the standard repertoire for managing death rattle. These interventions often entail positioning and repositioning people to facilitate postural drainage, gentle oropharyngeal suction, regular oral hygiene and timely, sensitive, therapeutic communication with family members and friends. However, while current NICE guidance(11) recommends non-pharmacological interventions, robust empirical evidence of their benefit and effectiveness in terms of easing secretions and thus the noise and supporting families is wanting.

For an intervention to be classified as being a treatment it must have some form of positive outcome- and generally this outcome needs to be measurable. If the outcome is equivocal this does not always stop us from giving such a treatment as a person can consent to having a treatment where the benefits are not clear. The absolute ethical and legal 'no' is when such a treatment causes harm.

In end of life care we have a further problem- whereby people can often not give us their consent as they are usually, when death is slow rather than a sudden decline,

unconscious and unable to communicate. In these circumstances we work on best interest decisions. For example, if a person is in pain- which we can tell from nonverbal signs- we give pain relief in the absence of consent. This is because no pain is judged to be better than to be in pain. Furthermore, we know that the treatments we have to offer for pain control are both safe and effective if given correctly.

Clearly, death rattle treatment presents clinicians with problems. We are unclear about how much the person suffers and how effective the treatments are. Further, people have death rattle when they are unconscious- and are therefore unable to give us consent. Therefore, to decide on best interests is not entirely defensible. It is perceived that for the person not to have death rattle is helpful for the family, but we do not know if the treatments we use work and therefore, help the family.

All the above highlight that there is an ethical need and moral imperative for further research of death rattle given the problems that *treating* it presents us with. To not do this and to continue with our current practice is unacceptable, unethical and amoral. If we are to be truly person centred and work in an evidence based, ethical way and improve palliative care for all then we cannot just avoid studies we think are 'too hard'.

We suggest:

1. Core outcome set to ensure all studies can be compared and are clinically relevant.
2. Evaluation of non-pharmacological interventions since these do not have the side effects which are cited for antimuscarinics.

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Conflicts of interest

no conflicts of interest

Reference List

* Of special interest

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1. Johnston B, Lawton S, McCaw C, Law E, Murray J, Gibb J, et al. Living well with dementia: enhancing dignity and quality of life, using a novel intervention, Dignity Therapy. *International Journal of Older People Nursing*. 2016;11(2):107-20.
2. Johnston B, Narayanasamy M. Exploring psychosocial interventions for people with dementia that enhance personhood and relate to legacy- an integrative review. *BMC Geriatr*. 2016;16:77.
3. Ellershaw JE, Sutcliffe JM, Saunders CM. Dehydration and the dying patient. *J Pain Symptom Manage*. 1995;10(3):192-7.
- * 4. Wee B, Hillier R. Interventions for noisy breathing in patients near to death. *Cochrane Database Syst Rev*. 2008(1):Cd005177.
Cochrane review which has been updated
5. Watts T, Jenkins K, Back I. Problem and management of noisy rattling breathing in dying patients. *Int J Palliat Nurs*. 1997;3(5):245-52.
6. Wee BL, Coleman PG, Hillier R, Holgate SH. The sound of death rattle I: are relatives distressed by hearing this sound? *Palliat Med*. 2006;20(3):171-5.
7. Wee BL, Coleman PG, Hillier R, Holgate SH. The sound of death rattle II: how do relatives interpret the sound? *Palliat Med*. 2006;20(3):177-81.
8. Shimizu Y, Miyashita M, Morita T, Sato K, Tsuneto S, Shima Y. Care strategy for death rattle in terminally ill cancer patients and their family members: recommendations from a cross-sectional nationwide survey of bereaved family members' perceptions. *J Pain Symptom Manage*. 2014;48(1):2-12.
9. Campbell ML. Assuaging listener distress from patient death rattle. *Ann Palliat Med*. 2019;8(Suppl 1):S58-s60.
10. Campbell ML, Yarandi HN. Death rattle is not associated with patient respiratory distress: is pharmacologic treatment indicated? *J Palliat Med*. 2013;16(10):1255-9.
11. Guidelines NifHaCEC. End of life care for adults: Quality Standard. London: National Institute for Health and Care Excellence (UK)
Copyright (c) 2011 National Clinical Guideline Centre.; 2011. Available from: <https://www.nice.org.uk/guidance/qs13/resources/end-of-life-care-for-adults-2098483631557>.
12. Consortium EMRPC. Management of respiratory secretions in the terminal phase 2016 31/07/19. Available from: <http://www.emrpcc.org.au/wp-content/uploads/2012/10/Management-of-Respiratory-Secretions-in-the-Terminal-Phase-May-2016.pdf>.
13. Care BCCFP. B.C. INTER-PROFESSIONAL PALLIATIVE SYMPTOM MANAGEMENT GUIDELINES 2017. Available from: https://www.fraserhealth.ca/-/media/Project/FraserHealth/FraserHealth/Health-Professionals/Professionals-Resources/Hospice-palliative-care/Sections-PDFs-for-FH-Aug31/9524-29-FH---Sym_Guide-RespiratoryCongestion.pdf.

14. Kolb H, Snowden A, Stevens E. Systematic review and narrative summary: Treatments for and risk factors associated with respiratory tract secretions (death rattle) in the dying adult. *J Adv Nurs*. 2018;74(7):1446-62.
15. Mercadante S. Death rattle: critical review and research agenda. *Support Care Cancer*. 2014;22(2):571-5.
16. Mercadante S, Marinangeli F, Masedu F, Valenti M, Russo D, Ursini L, et al. Hyoscine Butylbromide for the Management of Death Rattle: Sooner Rather Than Later. *J Pain Symptom Manage*. 2018;56(6):902-7.
- *17. van Esch HJ, van Zuylen L, Oomen-de Hoop E, van der Heide A, van der Rijt CCD. Scopolaminebutyl given prophylactically for death rattle: study protocol of a randomized double-blind placebo-controlled trial in a frail patient population (the SILENCE study). *BMC Palliat Care*. 2018;17(1):105.
This is a protocol but signifies a promising study
18. Bush SH, Grassau PA, Yarmo MN, Zhang T, Zinkie SJ, Pereira JL. The Richmond Agitation-Sedation Scale modified for palliative care inpatients (RASS-PAL): a pilot study exploring validity and feasibility in clinical practice. *BMC Palliat Care*. 2014;13(1):17.
19. Edwards AG, Russell IT, Stott NC. Signal versus noise in the evidence base for medicine: an alternative to hierarchies of evidence? *Family Practice*. 1998;15(4):319-22.
20. Watts T, Jones M, Wainwright P, Williams A. Methodologies analysing individual practice in health care: a systematic review. *Journal of Advanced Nursing*. 2001;35(2):238-56.
21. Kolb H, Snowden A, Stevens E, Atherton I. A retrospective medical records review of risk factors for the development of respiratory tract secretions (death rattle) in the dying patient. *J Adv Nurs*. 2018;74(7):1639-48.
22. Guidelines NifHaCEC. Care of Dying Adults in the Last Days of Life. London: National Institute for Health and Care Excellence (UK) Copyright (c) 2015 National Clinical Guideline Centre.; 2015.
- **23. Jansen K, Haugen DF, Pont L, Ruths S. Safety and Effectiveness of Palliative Drug Treatment in the Last Days of Life-A Systematic Literature Review. *J Pain Symptom Management*. 2018;55(2):508-21.e3.
key systematic review concluding a lack of evidence concerning effectiveness and safety of palliative drug treatments in dying patients
24. Baillie J, Anagnostou D, Sivell S, Van Godwin J, Byrne A, Nelson A. Symptom management, nutrition and hydration at end-of-life: a qualitative exploration of patients', carers' and health professionals' experiences and further research questions. *BMC Palliat Care*. 2018;17(1):60.
25. Watts T. End of life care in acute stroke settings: a qualitative investigation of bereaved family members experiences in Wales, UK.