



Death rattle: current experiences and non-pharmacological management – a narrative review

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Background and Objective: Death rattle (DR) is a common symptom in dying patients, caused by secretions in the upper airway. Experiences regarding DR differ among patients, relatives, and health professionals. However, evidence of patients', relatives', and health professionals' needs for DR management in order to improve their experiences is lacking. In addition, little is known about the actual effects of non-pharmacological interventions on DR intensity or DR-related distress. This narrative review aims to explore (I) the experiences and needs of patients, relatives, and health professionals regarding DR sound and its management; and (II) studies on non-pharmacological interventions in DR management.

Methods: Based on a PubMed literature search with the free-text term “death rattle”, nine studies published in the last ten years were included.

Key Content and Findings: No significant correlation between DR intensity and patients' respiratory distress could be found. Some relatives experience high levels of distress and express a need for DR care improvement. Health professionals are often influenced in their decision-making to intervene by external pressure or their need ‘to do something’. Both repositioning and explaining DR to relatives are seen as useful first-line non-pharmacological interventions by health professionals. The severity of DR does not improve when suctioning is performed before starting anticholinergics.

Conclusions: Variation in DR-related experiences and needs exists among relatives and health professionals. More research is needed into the effectiveness of non-pharmacological interventions for DR management and the most suitable measurement tools to objectify DR-related outcomes.

Keywords: Review; death rattle (DR); terminal care; experiences; non-pharmacological interventions

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Introduction

Death rattle (DR) is a common symptom in patients who are close to death. It is caused by an accumulation of secretions in the upper airway which dying patients cannot effectively cough up or ingest, as a result of diminished consciousness (1-3). Two subgroups of DR exist: DR type 1 or the 'real' DR due to predominantly salivary secretions and DR type 2 or the 'pseudo' DR due to predominantly bronchial secretions secondary to infection or pulmonary diseases (4,5). The reported prevalence of DR in general varies considerably, averaging around 50% (6-8).

The way DR is experienced can differ between patients, relatives, and health professionals. Since patients have a decreased consciousness when DR develops, one could assume they might not be aware of the sound (9,10). However, the precise patients' perception is difficult to evaluate (1). To date, there is no evidence available about the association between DR and respiratory distress (1,9,11). DR-related experiences among relatives and health professionals vary. Regarding relatives, some of them report DR as a distressing symptom, possibly related to their judgement of whether the patient is comfortable. Other relatives think of it as a useful warning sign of imminent death (2,12,13). DR can also impact health professionals, influencing their choice of whether or not to intervene (2,14). However, evidence of patients', relatives', and health professionals' needs for DR management in order to improve their experiences is lacking.

Regarding pharmacological interventions for DR management, anticholinergics are the most common drug of choice. A recent randomized controlled trial showed their effectiveness when given prophylactically (15). However, in current practice, anticholinergics are mostly administered when DR is already onset, despite the fact that current evidence does not support their effect when started after the occurrence of DR (1-3,16). The most frequently used non-pharmacological interventions in DR management are repositioning of the patient, suctioning of secretions, reducing hydration levels, and communication about DR with relatives (2,3,17). To date, little is known about the actual effect of these non-pharmacological interventions on DR intensity or on the distress perceived by relatives and health professionals related to DR.

Therefore, this narrative review aims to explore (I) the current experiences and needs of patients, family and health professionals related to DR sound and its management; and (II) studies on non-pharmacological

interventions in DR management. We present this article in accordance with the Narrative Review reporting checklist (available at <https://apm.amegroups.com/article/view/10.21037/apm-23-507/rc>).

Methods

We conducted a search in Medline via PubMed with the free-text term "death rattle" on January 3rd, 2023, and included papers published in the last ten years. First, all duplicates were removed and title and abstract screening was performed by two independent researchers (L.M. and E.O.). Conflicts were resolved with a third researcher (M.D.R.). Second, full texts were assessed based on predetermined selection criteria. The search strategy summary is provided in *Table 1* and a screening procedure is provided in *Figure 1*. Extracted data included: first author, country, year of publication, study design, setting, population, in- and exclusion criteria, sample sizes, objectives and results concerning measurement tools used, experiences of DR and non-pharmacological interventions. As this is a narrative review, no meta-analysis was conducted.

Results

Nine studies were included in this review: seven observational and two qualitative studies. A summary of the included studies is shown in *Table 2*.

We found one study reporting on the perceived patients' experiences of DR (6). This prospective observational study evaluated the relationship between DR intensity, scored by the Death Rattle Intensity Scale (DRIS), and patients' respiratory distress, evaluated by the Respiratory Distress Observation Scale (RDOS). No differences were found in respiratory distress when comparing patients with and without DR, nor was there a significant correlation between DR intensity and respiratory distress (6).

Three studies focused on bereaved relatives' experiences regarding different aspects of DR and its management (18-20). A qualitative interview study, by van Esch *et al.* [2020], found no positive experiences of the sound of DR and reported that most relatives had experienced DR as a distressing symptom. Other than the actual sound of DR, insecurities about the burden of DR for the patient, a longer duration of DR, and previous experience with DR were also found to negatively impact relatives' experiences. The amount and quality of information given by health professionals did not seem to influence relatives' experience

Table 1 The search strategy summary

Items	Specification
Date of search	January 3 rd , 2023
Databases and other sources searched	PubMed
Search terms used	Free text search term: "death rattle" Filter: 10 years
Timeframe	2013–2023
Inclusion and exclusion criteria	Inclusion Language: Dutch and English Reporting on: (I) patients', relatives', or health care professionals' experiences of DR; or (II) non-pharmacological interventions Exclusion Study type: literature reviews, study protocols, commentaries and case reports Wrong endpoints
Selection process	Title and abstract screening: two independent researchers (L.M. and E.O.) Full text screening: two independent researchers (L.M. and E.O.) Consensus: through discussions with third researcher (M.D.R.)

DR, death rattle.

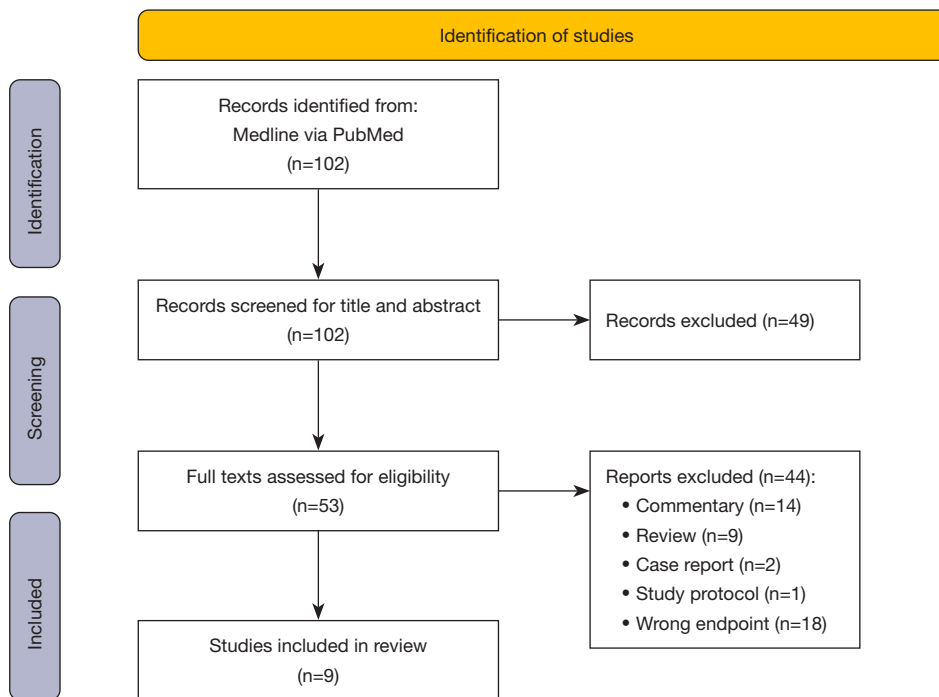


Figure 1 PRISMA flowchart of screening procedure and identified studies for inclusion.

Table 2 General characteristics of included studies and reported results

Study, country	Design	Objective	Setting population sample	Inclusion and exclusion	Results		
					Measurement tool	Experiences	Non-pharmacological interventions
Campbell <i>et al.</i> , 2013, (6), United States	Prospective, observational study	To determine if patients with naturally occurring DR experience respiratory distress	Setting <ul style="list-style-type: none"> • Palliative care service • Inpatient hospice unit • VAMC Population <ul style="list-style-type: none"> • Dying patients with and without DR Sample: n=71	Inclusion <ul style="list-style-type: none"> • PPS =10 Exclusion <ul style="list-style-type: none"> • Artificial airway • Secondary source of DR • Confounding etiology for risk of respiratory distress 	DRIS <ul style="list-style-type: none"> • DR intensity RDOS <ul style="list-style-type: none"> • Respiratory distress 	Patients <ul style="list-style-type: none"> • DR in 32 patients • No differences in RDOS when patients with and without DR were compared (P=0.143) • No correlation between DRIS- and RDOS-scores (P=0.477) 	–
van Esch <i>et al.</i> , 2020, (18), Netherlands	Semi-structured, phenomenological interview study	To gain a better understanding in bereaved relatives' experiences regarding DR	Setting <ul style="list-style-type: none"> • 13 clinical sites Population <ul style="list-style-type: none"> • Bereaved relatives Sample: n=19	Inclusion <ul style="list-style-type: none"> • DRIS ≥1 		Bereaved relatives <ol style="list-style-type: none"> 1. Experience of DR 2. Previous DR experiences 3. Information and communication 4. Burden for patient 5. Concerns about how long it would last 6. Impact of other symptoms 	Information and communication <ul style="list-style-type: none"> • Experience of DR does not seem to be influenced by the amount or quality of information given by health professionals
Yamaguchi <i>et al.</i> , 2022, (19), Japan	Prospective, multicenter cohort study, cross-sectional, multicenter survey study	To explore the consistency between physician-rated and bereaved family-perceived intensity of DR, to explore the relationship between DR intensity and bereaved family's distress, and to explore bereaved family's experienced related to suctioning for DR	Setting <ul style="list-style-type: none"> • PCUs Population <ul style="list-style-type: none"> • Bereaved relatives • Terminally ill patients with cancer Sample: n=297	Not specified	DRIS <ul style="list-style-type: none"> • DR intensity • Low accuracy of prediction (AUC =0.62) 	Bereaved relatives <ul style="list-style-type: none"> • Family-perceived intensity of DR was generally lower than physician evaluated DR intensity • Poor correlation between physician-evaluated and family-perceived DR intensity 	Suctioning performed for 85.7%; Experiences and feelings of bereaved relatives related to suctioning for DR: <ul style="list-style-type: none"> - 77.5% felt DR sound decreased after suctioning - 73.0% thought patient became more comfortable - 25.7% felt a strong need for care improvement related to suctioning for DR ° Positively correlated: gender of bereaved relative and patient showing a distressing face during suctioning ° Negatively correlated: having enough discussions with health professionals, feeling that suctioning is performed as gently as possible

Table 2 (continued)

Table 2 (continued)

Study, country	Design	Objective	Setting population sample	Inclusion and exclusion	Results		
					Measurement tool	Experiences	Non-pharmacological interventions
Shimizu <i>et al.</i> , 2014, (20), Japan	Cross-sectional, multicenter survey study	To clarify emotional distress levels of bereaved family members and their perceptions of the need for care improvement and to explore factors influencing these perceptions	Setting <ul style="list-style-type: none"> • 95 PCUs Population <ul style="list-style-type: none"> • Bereaved relatives of cancer patients Sample: n=390	Inclusion <ul style="list-style-type: none"> • PCU as place of death • ≥20 years old both patient and family members Exclusion <ul style="list-style-type: none"> • No permanent address • Serious psychological distress • Unable to complete questionnaire 	Categorical scale <ul style="list-style-type: none"> • DR intensity 5-point Likert scale <ul style="list-style-type: none"> • Family distress level 4-point Likert scale <ul style="list-style-type: none"> • Need for improved care 	Bereaved relatives <ul style="list-style-type: none"> • 181 experienced DR - 66% had high distress levels - 53% felt strong need for care improvement - 37% reported patient discomfort - 64% thought patient was drowning - 72% thought death was imminent Statistically significant factors contributing to high family distress levels <ul style="list-style-type: none"> - Patient age - Marital relationship - Fear of death - Distressing interpretations of DR Statistically significant factors contributing to high levels of family reported need for care improvement <ul style="list-style-type: none"> - Patient age - Loud and long DR - Associated discomfort - Experiences of inadequate nursing care 	Suctioning <ul style="list-style-type: none"> • 162 respondents' relatives underwent suctioning - 62% reported patient discomfort - 72% reported temporarily improvement of DR - 25% reported lasting improvement of DR Explaining to relatives <ul style="list-style-type: none"> • 181 respondents - 56% reported inadequate explanation about DR being a natural phenomenon - 33% reported a lack of explanation about its causes
Hirsch <i>et al.</i> , 2013, (21), United Kingdom	Focus group study	To explore the attitudes of health professionals towards treatment of DR and issues that might influence their decision-making to prescribe or administer pharmacological or non-pharmacological interventions	Setting <ul style="list-style-type: none"> • 2 PCUs Population <ul style="list-style-type: none"> • Ward inpatient nursing staff • Nurse specialists from home-care teams • Medical staff working with inpatient nursing staff and homecare teams Sample: n=30	Not reported	–	Health professionals <ol style="list-style-type: none"> 1. Influence of clinical knowledge and assessment 2. Repositioning and explanation as an intervention for DR 3. Pressure from colleagues 4. The need 'to do' something 5. Perceived risks and benefits of anticholinergics for DR 6. Beliefs about the effectiveness of anticholinergics for DR 	Repositioning <ul style="list-style-type: none"> • Useful first line intervention • Relatives caring for patients at home can be reluctant because of fear that he/she might die during the process Explaining to relatives <ul style="list-style-type: none"> • Useful first line intervention • More likely to be carried out in the home environment • Concern about increasing relatives' and patients' anxiety by talking about DR before it happens

Table 2 (continued)

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Study, country	Design	Objective	Setting population sample	Inclusion and exclusion	Results		
					Measurement tool	Experiences	Non-pharmacological interventions
Yamaguchi <i>et al.</i> , 2023, (22), Japan	Prospective, multicenter cohort study	To investigate the effectiveness of anticholinergics for DR and to explore the effect of suctioning on DR improvement before initiating treatment with anticholinergics	Setting <ul style="list-style-type: none"> • 23 PCUs Population <ul style="list-style-type: none"> • Terminally ill patients with cancer Sample: n=196	Inclusion <ul style="list-style-type: none"> • Locally advanced or metastatic cancer • ≥18 years old • first admitting to PCU Exclusion <ul style="list-style-type: none"> • DRIS ≥2 • Scheduled discharge <1 week 	DRIS <ul style="list-style-type: none"> • DR intensity 	–	Suctioning in anticholinergics group (n=81) <ul style="list-style-type: none"> • Non-suctioning group (n=34) - 67.6% improved DR <ul style="list-style-type: none"> • Suctioning group (n=46) - 48.9% improved DR <ul style="list-style-type: none"> • Missing value (n=1) Suctioning before starting anticholinergics does not influence effectiveness
Dayan <i>et al.</i> , 2021, (23), Israel	Prospective, observational study	To characterize the practice of subcutaneous hydration and explore the connection between the provision of subcutaneous hydration and DR incidence	Setting <ul style="list-style-type: none"> • Hospice home care Population <ul style="list-style-type: none"> • Hospice patients Sample: n=120	Inclusion <ul style="list-style-type: none"> • ≥15 years old • Presumed impending death <6 days Exclusion <ul style="list-style-type: none"> • Patients who did not die at home 	–	–	SCH <ul style="list-style-type: none"> • Men more likely to receive SCH (P=0.09) • Oral fluid intake is negatively correlated with SCH provision <ul style="list-style-type: none"> • Patients who received SCH are more likely to develop DR, but a significant connection between SCH provision and DR was not demonstrated
Matsunuma <i>et al.</i> , 2020, (24), Japan	Non-interventional survey study	To investigate the perceptions of palliative care physicians about their practices and opinions regarding pharmacological and non-pharmacological management of DR	Setting <ul style="list-style-type: none"> • Not specified Population <ul style="list-style-type: none"> • Certified palliative care physicians Sample: n=10	Not specified	5-point Likert scales <ul style="list-style-type: none"> • Suctioning • Repositioning 	–	Suctioning <ul style="list-style-type: none"> • 29% would often perform suctioning in DR type 1 • 46% would often perform suctioning in DR type 2 Repositioning <ul style="list-style-type: none"> • 51% would very often perform repositioning in DR type 1 and 2
Likar <i>et al.</i> , 2017, (25), Austria	Non-interventional survey study	To explore relevant, influencing clinical factors on the characteristics of DR	Setting <ul style="list-style-type: none"> • 1 PCU Population <ul style="list-style-type: none"> • Hospitalized patients with cancer Sample: n=10	Inclusion <ul style="list-style-type: none"> • Malignant tumor disease 	VRCS <ul style="list-style-type: none"> • DR intensity 	–	Fluid administration <ul style="list-style-type: none"> • No significant differences between variables concerning the incidence of DR

DR, death rattle; VAMC, Veterans Administration Medical Center; DRIS, Death Rattle Intensity Scale; RDOS, Respiratory Distress Observation Scale; SCH, subcutaneous hydration; PCU, palliative care unit; PPS, Palliative Performance Scale; VRCS, Victoria Respiratory Congestion Scale; AUC, area under the curve.

of DR. However, when other symptoms such as dyspnea, restlessness, or delirium prevailed, the experience of DR seemed less burdensome for relatives (18). Yamaguchi *et al.* [2022] reported a poor correlation between physician-evaluated and bereaved family-perceived DR intensity, with generally lower scores for bereaved family perceptions of DR intensity. According to the researchers, this suggests relatives' emotional distress might not be correlated with DR intensity (19). Lastly, Shimizu *et al.* [2014] investigated DR related emotional distress levels of bereaved relatives and their perceptions of the need for DR care improvement. They reported that 66% of bereaved relatives who experienced DR, had high levels of distress and 53% had a strong need for DR care improvement (20).

Health professionals' attitudes towards and decision-making in prescribing or administering pharmacological or non-pharmacological interventions was described in one study (21). This study reported that health professionals are often influenced in their decision making to prescribe or administer medication by external pressure from colleagues or their own need to 'do something', even if they thought it was not beneficial for the patient (21).

Regarding studies on non-pharmacological interventions, we found one study that investigated the effectiveness of a non-pharmacological intervention, suctioning, as their secondary endpoint (22). The effect of suctioning on DR improvement before starting anticholinergics was tested, showing that the severity of DR did not improve when suctioning was performed ($P=0.13$) (22). No additional studies were found reporting on the observed effect of other non-pharmacological interventions.

Seven studies reported on experiences related to at least one non-pharmacological intervention for DR, either as a primary (19,23,24) or secondary (18,20,21,25) endpoint.

The perceived role of repositioning of the patient in DR management was reported in two studies (21,24). The first study, a survey study among certified palliative care physicians showed that 51% of participants would (very) often perform repositioning as an intervention for DR (24). The other study, a focus group study by Hirsch *et al.* [2013] mentioned that specialist health professionals from palliative care units agreed on repositioning patients as a useful first line intervention (21).

Three studies reported on different aspects of suctioning as an intervention to reduce DR intensity (19,20,24). Matsunuma *et al.* [2020] found that 29% and 46% of Japanese palliative care physicians would often perform oropharyngeal suctioning for type 1 and type 2 DR,

respectively (24). Shimizu *et al.* [2014] focused on relatives' experiences related to suctioning. Of family members whose relative underwent suctioning, 62% reported patient discomfort during suctioning, 72% reported temporary improvement and 25% enduring improvement of DR after suctioning (20). In a study by Yamaguchi *et al.* [2022], 77.5% of the relatives thought the sound of DR decreased and 73% reported that patients became more comfortable after suctioning. One quarter, 25.7%, of bereaved relatives experienced a need for care improvement related to suctioning. A positive correlation was found with the patient showing a distressing face during suctioning. Having thorough discussions about suctioning with physicians or nurses and a perceived gentle performance of suctioning was found to be negatively correlated with bereaved relatives' need for care improvement related to suctioning (19).

The effect of fluid administration during end-of-life care was reported on in two studies (23,25). The first explored the correlation between provision of subcutaneous hydration 6 days before death and the incidence of DR. While they found a positive correlation between subcutaneous hydration and DR incidence, no statistically significant relationship was found (23). The other study reported on the effect of relevant influencing clinical factors, as among which fluid administration, on DR's characteristics. No significant differences between variables concerning DR were found (25).

Three studies described the experiences related to communication and information about DR as a non-pharmacological intervention (18,20,21). Hirsch *et al.* [2013] found that explaining DR to relatives was perceived as a useful first line intervention by health professionals (21). The survey study of Shimizu *et al.* [2014] showed that higher distress levels were reported by family members who were unaware about DR being a natural phenomenon, with 56% of participants reporting an inadequate explanation of it being a natural phenomenon and 33% reporting a lack of explanation about DR causes (20). Lastly, van Esch *et al.* [2020] showed that relatives' experiences of DR do not seem to be influenced by the amount and quality of information given by health professionals (18).

Discussion

This narrative review aimed to explore the current experiences and needs of patients, family and health professionals related to DR sound and its management and to describe non-pharmacological interventions in DR

management. Overall, we demonstrated that DR-related experiences differ among patients, relatives, and health professionals. Some bereaved relatives express a need for DR care improvement but to date, the effectiveness of non-pharmacological interventions for DR management remains unclear.

An editorial by Lowe and Hanson [2021] states that one should acknowledge that the internal experience of the dying, nonverbal patient cannot be fully known (16). As the hearing of a dying patient seems to be preserved throughout the dying process, there is always the possibility the patient can hear their own DR. However, the capacity for awareness during the unresponsive period leading up to a “natural” death is unknown (26,27). So it may be that one hears its own DR, but is not capable of ‘listening to it’ anymore. The assumption that patients do not experience distress related to DR sound, due to their decreased consciousness, seems to be confirmed by the one study found focusing on patients’ experience of DR by Campbell *et al.* [2013], who used the RDOS to measure patients’ distress (6). This scoring scale has strong validity, reliability and cut-point determination psychometrics and is not subject to investigator interpretation, unlike other scales used in this setting, which are subject to the interpretation of health professionals which can inherently lead to an (inter)observer bias, such as the DRIS evaluating DR intensity (10,28).

Although it remains unclear how patients experience DR, we found four studies reporting that DR can cause significant distress and concerns in relatives (18-21). Again, an important consideration in the interpretation of these findings is the measurement tools used in these studies. For example, Yamaguchi *et al.* [2022] examined the sensitivity and specificity of the DRIS score for detecting bereaved relatives’ distress levels related to DR and found a low accuracy of prediction [area under the curve (AUC) =0.62]. This strongly indicates that the DRIS is not a useful tool for detecting DR-related distress levels in bereaved relatives and that DR intensity might not be an appropriate outcome measure to quantify DR-related distress (19). Additionally, in two of the included studies, questionnaires consisting of Likert scales were used to capture perceived distress in bereaved relatives and were developed by the research team based on literature review and discussion among specialists in palliative care (e.g., physicians and nurses) (20,24). We could not find any standardized or validated questionnaire for measuring relatives’ DR-related distress. Therefore, we suggest that future research should focus on the development of a reliable measurement tool to objectify

DR-related outcomes. Furthermore, the contributing factors of higher distress levels among relatives reported by both Shimizu *et al.* [2014] and van Esch *et al.* [2020] should be taken into account and evaluated in future research. Reported contributing factors are (I) relatives’ own fear of imminent death; (II) making distressing interpretations about DR; (III) unawareness of DR being a natural phenomenon; (IV) insecurities about the burden of DR for the patient; (V) previous experiences with DR; (VI) a longer duration of DR; (VII) a younger patient age; and (VIII) being married to the patient. It is important for health professionals to become aware of these factors to identify relatives with a greater chance of experiencing distress. Secondly, most of these factors, except for the patient’s age and the relationship status with the patient, could possibly be alleviated or even prevented by either general or factor specific interventions, such as the provision of adequate nursing care as well as accurate information and communication (18,20). This is supported by a recent survey showing that relatives provided with information about the dying phase have more understanding about this phase and have a better ability to make informed decisions. In addition, relatives feel more comfortable about staying with the dying patient when prepared about the situation by clear communication (29). However, it should be noted that van Esch *et al.* [2020] mentioned that information given by health professionals did not seem to influence relatives’ experience of DR (18). More research is needed to further determine which relatives are most in risk of distress and how to best identify them. Additionally, a stronger body of evidence is needed regarding the efficacy of non-pharmacological interventions, such as education and communication, to reduce DR-related distress levels in relatives.

Currently, there is only limited insight in patients’, relatives’ or health professionals’ needs regarding DR care. One Japanese study reported that half of bereaved relatives experience a strong need for DR care improvement. One major contributing factor of a higher family-reported need for DR care improvement was the family members’ experience of inadequate nursing care (20). This emphasizes the importance of well-trained nursing staff in end-of-life care and the need to educate relatives about the course of end-of-life care. Overall, additional research into the needs of both patients, relatives, and health professionals to optimize DR care is warranted.

This review found that health professionals’ decision-making regarding interventions seems to be influenced by

reasons not directly related to relieving the distress of the dying patient (21). This has also been reported in other research, suggesting that health professionals' responses and decisions are influenced by the way in which they make sense of DR and their own perception of its effect on relatives rather than on patients (2,14). It seems that the need 'to do something' is so deeply ingrained in health professionals' culture of care that it is necessary to make them aware of their own perceptions and behaviors, as they are the ones carrying out DR care for both patients and relatives. A better understanding of contributing factors to health professionals' decision-making seems needed in order to optimize current DR management.

A recent paper discusses the thought processes and clinical approach for pharmacological DR management of three experts in the field. A disparity in their opinions exists, as they have different ethical considerations in mind when making decisions (30). Taking into account the principle of nonmaleficence, some may consider it morally questionable to treat a patient, of whom the level of DR-related distress is not known, with medication that may result in patient discomfort or distress through associated side effects (e.g., dry mouth, constipation, urinary retention) and of which no strong evidence exists to support their use in DR treatment once DR is onset (3,11,30-34). One expert in the paper suggests the prophylactic treatment of DR as a promising strategy, as recent evidence suggests anticholinergics may be more effective if used as prophylaxis for DR (15,16,30,35). However, identifying patients at high-risk of developing DR is difficult, so selective prophylactic treatment of only those patients is currently not possible (11,31). With the prevalence of DR estimated at 50% on average, systematically treating all patients prophylactically with medication would entail that one out of two patients could be treated unnecessarily. This brings up the ethical issue of medical futility defined as the clinical action which does not serve a useful purpose in attaining a specified goal, in this case being the patient's comfort (34). Finally, another clinical justification of using medications in the treatment of DR seems to be assuaging the distress of relatives (30). However, when choices to intervene are based on helping relatives rather than the patient this implies another ethical dilemma. As some may think treating a patient to decrease their DR sound is a helpful way of assuaging listeners' distress, others might consider this as maleficent and would rather focus on interventions directly focused on relatives (30).

With all these ethical and practical considerations surrounding pharmacological management of DR, our

group believes the priority for research should be aimed towards nonpharmacological management for DR treatment, concerning interventions such as repositioning of the patient, suctioning, and comprehensive communication strategies (3,10,32). However, the only study investigating the effectiveness of suctioning before starting anticholinergics reported no improvement of DR due to the intervention (15). Hirsch *et al.* [2013] suggested that repositioning of patients and communication with relatives can be useful first line interventions, yet the effect on perceived DR intensity or distress levels among relatives or health professionals has not been studied (21). One included study found a positive correlation between subcutaneous hydration and DR incidence (23). A recent retrospective study supports these findings, with a high hydration level (>500 mL/day) one week before death significantly associated with a higher incidence of DR 48 hours before death (36). However, to our knowledge, no studies exist focusing on the effectiveness of reducing hydration levels for DR incidence. As such, this supports the conclusion of several other reviews in stating that there is an urgent need to study the effectiveness of non-pharmacological interventions for DR management (2,31,32).

Another important point of concern is the outcome measures used in the evaluation of (non-pharmacological) interventions. Currently, the mostly used outcome measure is a decrease in DR intensity. For its measurement, the Victoria Respiratory Congestion Scale (VRCS) and the DRIS are the most commonly used tools (6,19,22,25). These are two numeric scales which need to be filled out by a health professional, which can lead to (inter)observer bias. A recent validation study by Tantiwatniyom *et al.* [2022] showed criterion-related validity and reliability of the Thai VRCS to objectively assess DR intensity, but this is the only validation study we could find (37). Another and possibly more useful outcome measure could be the alleviation of DR-related distress within bereaved relatives or health professionals. A problem arises here, as DRIS is often used to capture DR-related distress in relatives and as earlier discussed; DR intensity might not be an appropriate outcome measure to quantify DR-related distress (4). Therefore, researchers should first reflect on the outcome measure they want to objectify in order to determine which measurement tool is most appropriate to use.

Two important methodological limitations of this narrative review need to be addressed. First, this review only included articles published in the last ten years. This decision was based on the availability of the systematic

review of Lokker *et al.* [2014], in which articles published up to August 2012 were included (2). This narrative review aimed to provide researchers and health professionals with new or additional insights into DR management. Second, we did not conduct a multicomponent search strategy in different databases. Rather we used a targeted approach based on the most relevant key word in PubMed, which was in line with the scope of this narrative review, i.e., to map the most recent literature on DR and formulate avenues for further research. Hence, some key papers might have been missed. In addition, some methodological elements of the included studies should be considered in the interpretation of the results. First, three of the ten included studies were conducted in Japan. Given that DR experiences might be subject to cultural differences, the generalizability of the results might be limited. Second, all included articles on relatives' experiences related to DR were carried out retrospectively with bereaved family members. This may have caused recall bias in the bereaved family members' responses. However, conducting research in a terminal setting with patients, relatives and health professionals remains a challenge because of both ethical and methodological considerations (38).

Conclusions

This narrative review provides insight into some of the more understudied topics related to DR management and suggest avenues for further research. The assumption that patients are not disturbed by DR because of a decreased consciousness remains. Therefore, we should focus on the experiences and needs of relatives and health professionals. Variation in DR related distress within relatives exist, which can be influenced by different contributing factors. A better understanding of these factors seems needed in order to optimize current DR management. Also, health professionals are influenced in their decision-making to intervene for reasons not directly related to relieving the distress of the dying patient. Awareness of these behaviors is necessary to enhance DR care. The effectiveness of non-pharmacological interventions remains unclear, indicating more research is needed.

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Footnote

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