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(Citation)

Japanese Journal of Clinical Oncology, 52(7):774-778

(Issue Date)

2022-04-22

(Resource Type)

journal article

(Version)

Accepted Manuscript

(Rights)

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This is a pre-copyedited, author-produced version of an article accepted for publication in The impact of death rattle on bereaved families: not the sound itself, but the resonance with their feelings following peer review. The version of record...

(URL)

<https://hdl.handle.net/20.500.14094/0100483311>



The impact of death rattle on bereaved families: Not the sound itself, but the resonance with their feelings.

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Word count: 2246; Tables: 3; Figures: 1

Keywords: Death rattle, suctioning, bereaved family, palliative care unit

ABSTRACT

Background: This study aimed to explore 1) the consistency between physician-rated and bereaved family-perceived intensity of death rattle (DR), 2) the relationship between intensity of DR and the bereaved family's distress, and 3) the bereaved family's experience and feelings related to suctioning for DR.

Methods: We used matched data for deceased patients from a prospective cohort study of cancer patients admitted to a palliative care unit, and their bereaved families from a nationwide questionnaire survey in Japan. The intensity of DR using Back's score was evaluated prospectively by physicians and retrospectively by bereaved families.

Results: 1122 bereaved families answered (response rate: 66.7%). Of these, 297 reported the development of DR. The maximum intensity of DR evaluated by physicians and perceived by bereaved families was poorly correlated (Spearman correlation coefficient 0.188, $p = 0.082$). The optimal cut-off point of Back's score for detecting high-level distress was 1/2, with a low accuracy of prediction (area under the curve 0.62). More than 70% of bereaved families indicated suctioning reduced the intensity of DR, made patients comfortable and themselves relieved, while a similar proportion felt patients were in distress during suctioning. Families who felt suctioning was gently performed and discussed well whether to do suctioning with health care providers felt less needs for improvement.

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Conclusions: Bereaved family-perceived intensity of DR did not correlate to physician-evaluated intensity, and the intensity of DR itself seemed to poorly correlate to family distress. Gently performed suctioning based on sufficient discussion with families can help reduce family-perceived patient discomfort.

Mini Abstract

Bereaved family-perceived death rattle intensity did not correlate to physician-evaluated. It seemed to poorly correlate to family distress. Gently performed suctioning based on sufficient discussion can help reduce patients' discomfort.

INTRODUCTION

Death rattle (or noisy breathing) is noisy ventilation due to accumulation of secretion in the pharynx and/or airways. This symptom commonly occurs in the dying phase, with a reported prevalence of 13 to 92% in dying patients.¹ Death rattle is thought to predominantly occur due to the accumulation of salivary secretion in the pharynx in the absence of effective swallow reflexes from a decreased conscious level.² Usually, death rattle occurs in the last few days of life.³

Back score evaluates the intensity of noise, and is often used to evaluate death rattle in both the clinical and research environment.⁴ Previous studies have reported that patient caregivers often feel distress when hearing the sound of death rattle.⁵⁻⁸ However, some suggest that patients may not be aware of suffering caused from death rattle, because it usually develops in unconscious patients. From this stand point, the volume of death rattle itself may not be the important outcome. Yet, there is a paucity in data on whether there is a relationship between the volume of death rattle noise and the distress of their caregivers.

Another important issue related to death rattle is about suctioning for it. Since there is limited evidence in pharmacologic therapy for death rattle, suctioning for death rattle is often performed in daily practice,⁹ although there is no strong evidence that it is effective for death rattle and it may even cause adverse events to patients.¹⁰ Moreover, a previous

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study reported that it may cause distress for caregivers.⁶ However, detailed data about the exact experience and feeling of caregivers related to suctioning patients developing death rattle is lacking.

The aims of this study were to explore: 1) the consistency between physician-rated and bereaved family-perceived intensity of death rattle, 2) the relationship between the family-perceived intensity of death rattle and the bereaved family's distress, and 3) the bereaved family's experience and feelings related to suctioning for death rattle.

METHODS

Setting and Participants

We used the matched data of deceased patients and their bereaved families. Patient data were from the East Asian collaborative cross-cultural Study to Elucidate the Dying process (EASED) study, an international, multicenter, prospective, cohort study of advanced cancer patients at palliative care units (PCUs) in Japan, South Korea, and Taiwan.¹¹ Briefly, the EASED study consecutively enrolled adult cancer patients admitted for the first time to 38 PCUs (23 in Japan, 11 in South Korea, and 4 in Taiwan). We used only Japanese data for this study and patient recruitment were conducted from January 2017 to December 2017. In accordance with the ethical guidelines for human research of the Ministry of Health, Labor, and Welfare in Japan, informed consent from the patients was waived in Japan because of the completely observational nature of the study. And EASED study was approved by the institutional review board of Seirei Mikatahara General Hospital as a representative (Research No. 16-22) and all participating institutions in each country. Bereaved family data were from the Japan Hospice and Palliative Care Evaluation (J-HOPE) 4 study, a cross-sectional nationwide survey of bereaved family members of deceased cancer patients in Japan.¹² Briefly, J-HOPE 4 included bereaved families whose loved one died during year of 2017 at 233 institutions all over Japan, including 21 PCUs which participated in the EASED study. A self-reported questionnaire was sent by postal mail to bereaved families

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between May to June 2018 and we asked them to complete and return the questionnaire within 1 month. We sent a document explaining aims and procedures of the J-HOPE4 study along with the questionnaire, and the return of a completed questionnaire were considered as consent to participate. J-HOPE4 study including combined data analysis with EASED study was approved by the institutional review board of Tohoku University hospital as a representative (2017-2-236-1) and each participating institutions.

Measurements

The intensity of death rattle

The intensity of death rattle was evaluated by Back's score.⁴ Back's score consists of 4 categories: "inaudible" (0), "audible only very close to the patient" (1), "clearly audible at the end of the bed in a quiet room" (2), and "clearly audible at about 6 meters or at the door of the room" (3). We asked the primary responsible physician to evaluate Back's score every four hours prospectively when the patient developed a death rattle of Back's score 2 or more, up until 24 hour later or the patient's death, whichever came first. We also asked bereaved families of the patients to evaluate their perceived maximum intensity of the death rattle that their loved one developed during dying phase, according to Back's score by recalling.

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Distress related to death rattle

We asked bereaved families to rate the intensity of distress that they felt when their loved one developed a death rattle. We used a 5-point likert scale (1: not at all, 2: a little distressed, 3: somewhat distressed, 4: distressed, and 5: very distressed) for evaluating the intensity of distress following pervious study.⁶

Bereaved families' experiences and feelings about suctioning for death rattle

We asked bereaved families' experiences and feelings about suctioning for death rattle by rating six statements ("the sound of rattle decreased after suctioning" "patient became comfortable by suctioning" "patient showed a distressing face during suctioning" "you were relieved when the patient received suctioning" "you had enough discussion on whether to suction or not with physicians and nurses" and "suctioning was performed as gently as possible not to cause patient's suffering") using 5-point likert scale (1:disagree, 2: agree a little, 3:somewhat agree, 4: agree, and 5 strongly agree).⁶

We also asked them to rate their perceived need for care improvement related to suctioning for death rattle by using 4-point likert scale (1: no need for improvement, 2: some improvement needed, 3: considerable improvement needed, and 4: extreme improvement needed).⁶

Bereaved families' demographic data

We collected bereaved families' demographic data, including age, sex, relationship with the patient, education level, frequency of attendance at the patient's bedside during admission.

Statistical analysis

We calculated the mean physician-evaluated and bereaved family-perceived maximum Back's score with 95% confidence intervals (95% CIs). Then, we explored correlation between physician-evaluated and bereaved family-perceived maximum Back's score by using a Spearman correlation coefficient. We also calculated sensitivity and specificity of bereaved family-perceived Back's score for detecting their high-level of distress related to death rattle. We classified distressed and very distressed as high-level of distress. Then, receiver-operating characteristic (ROC) curves were used to identify optimal cutoff points.¹³ About bereaved families' experiences and feelings about suctioning for death rattle, we classified "agree" and "strongly agree" as agreement of statements and "considerable improvement needed" and "extreme improvement needed" as strong need for improvement. Then, we descriptively analyzed the proportion of agreement for each statement. We used a binominal logistic regression analysis to explore the factors influencing bereaved families perceived strong need for improvement of care related to suctioning. All statistical analyses

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were performed using SPSS for Windows, version 19.0 (IBM Japan Institute, Tokyo, Japan).

RESULTS

We sent the questionnaire by mail to 1681 bereaved families, and 1122 answered and returned (response rate: 66.7%). Of those, we analyzed 297 bereaved families who answered that the patient had developed a death rattle. The characteristics of participants (bereaved families and patients) are summarized in Table 1.

Correlation between physician-evaluated and bereaved family-perceived death rattle

We identified 89 patients who developed a death rattle of 2 or more in Back's score during their PCU admission and their bereaved families. The mean maximum intensity of death rattle evaluated by primary physicians and perceived by bereaved families were 2.39 (95%CI: 2.29-2.50) and 0.92 (95%CI: 0.70-1.14), respectively. The Spearman correlation coefficient was 0.188 ($p = 0.082$) between primary physician evaluated and bereaved family perceived maximum intensity of death rattle, which meant poor correlation.

Sensitivity and specificity of bereaved family-perceived Back's score for detecting their high-level of distress related to death rattle

Of the 297 respondents, 285 reported both their perceived Back's score and level of distress related to death rattle. We calculated sensitivity and specificity to determine the optimal cut-off point of a bereaved family-perceived Back's score for detecting their high-level of

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distress related to death rattle (Table 2). The optimal cut-off point was half the Back's score, according to the Youden index.¹³ The area under the curve was 0.62, which meant low accuracy of the prediction.

Bereaved families' experiences and feelings about suctioning for death rattle

According to families, suctioning for death rattle was reported to be performed for 245 of 286 participants (85.7%). Of those, 77.5% felt that the sound of rattle decreased after suctioning, 73.0% thought that the patient became more comfortable by suctioning, 75.1% felt that the patient showed a distressing face during suctioning, 76.7% thought that they were relieved when the patient received suctioning, 54.1% thought that they had enough discussion on whether to suction or not with physicians and nurses, and 77.4% felt that suctioning was performed as gently as possible so as not to cause patient suffering (Fig 1).

Sixty-three (25.7%) of 245 who answered that their loved one were performed suctioning for death rattle felt a strong need for improvement of care related to suctioning for death rattle. Results of binominal logistic regression analysis showed that the gender of bereaved family member (female) and feeling that the patient showed a distressing face during suctioning had positive correlation, and having enough discussion on whether to suction or not with physicians and nurses and feeling that suctioning was performed as gently as possible so as not to cause patient suffering, had a negative correlation to bereaved families

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perceived strong need for improvement of care related to suctioning (Table 3).

DISCUSSION

This study had several major findings. First, we found poor correlation between physician-evaluated and bereaved family-perceived intensity of death rattle. Moreover, bereaved family perception of death rattle intensity was generally lower than physician evaluation. The other major finding of this study was that bereaved family-perceived death rattle intensity was not a useful tool for evaluating their distress related to death rattle. As patients who develop death rattle usually have decreased consciousness,¹⁴ it is thought that patients themselves may not be aware of the sound of death rattle, and are unlikely to feel discomfort related to death rattle.^{6,8} Thus, there is an aspect that the target of death rattle treatment is not the sound itself, but the distress of the patient's family and other caregivers. Indeed, the majority of patient families reported their distress related to death rattle during the patient's dying phase.^{6,8,15} However, according to results of current study, it was suggested that families' perception of death rattle intensity would be inaccurate and the intensity of death rattle itself might not correlated to the distress of families. In consideration of current and previous results,^{6,16} we have to target not only the intensity of death rattle, but also explanation about the nature of death rattle and appropriate care for death rattle to reduce the family distress related to it.

The third major finding of this study was more than 70% of bereaved families perceived that suctioning reduced the intensity of the death rattle and made the patient comfortable

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and themselves relieved. On the other hand, a similar proportion felt that patients were in distress during suctioning. In addition, the more patient's distress bereaved families perceived during suctioning, the more need for improvement of care related to suctioning they felt. On the other hand, the more gently performed and thoroughly discussed with health care providers about suctioning they perceived, the less need for improvement they felt. These results suggest it is important to perform suctioning only based on enough discussion with patient families and as gently as possible so as not to cause patient suffering.

There were several limitations in this study. First, because the data from bereaved families were generally based on recall after the lapse of a certain period from patients' death, the recall bias cannot be excluded. Thus, we should conduct a prospective study to overcome the risk of recall bias. Second, although a good response rate, participants in this study were limited to bereaved families and patients who died at 21 PCUs in Japan. Thus, a selection bias might be influencing the results. Moreover, since this study was conducted in Japan, the results might not be generalized globally. Third, although one of the strengths of this study was using combined data of prospective cohort data of patients and their bereavement families' survey data, we included only 89 dyad of patients and their bereaved families who developed death rattle of Back's score 2 or more in the analysis of correlations between physician-evaluated and family-perceived intensity of death rattle.

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Since we evaluated and followed patients' death rattle intensity only after its intensity became a Back's score of two or more in the patient cohort, we could not access the data of patients whose maximum death rattle intensity was 0-1 in Back's score. Thus, this may significantly influence the result.

In conclusion, we found that the bereaved family-perceived intensity of death rattle did not correlate to physician-evaluated intensity, and the intensity of death rattle itself seemed to poorly correlate to family distress. Thus, we have to evaluate family distress multi-dimensionally when we face dying patients with a death rattle. In addition, although the majority of families thought suctioning for death rattle caused discomfort to the patients, they had a positive impression to suctioning at the same time. Thus, when we consider suctioning, we have to perform it gently and be careful not to cause any patient discomfort on the basis of sufficient discussion with families.

CONFLICTS OF INTEREST

All of the authors declare that they have no conflicts of interest.

FUNDING

This study was supported by a Grant-in-Aid from the Japan Hospice Palliative Care Foundation.

AUTHOR CONTRIBUTIONS

Conception and design: Takashi Yamaguchi, Masanori Mori, Tomohiro Nishi, Yoshiyuki Kizawa, Satoru Tsuneto, Yasuo Shima, and Mitsunori Miyashita.

Collection and assembly of data: Takashi Yamaguchi, Isseki Maeda, Kento Masukawa, and Mitsunori Miyashita.

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Manuscript writing: All authors.

Final approval of manuscript: All authors.

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Table 1. Characteristics of bereaved families and patients.

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Table 2. Sensitivity and specificity of bereaved family-perceived Back's score for detecting high level of distress related to death rattle.

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Table 3. Factors influencing bereaved families perceived needs for improving care related to suctioning for death rattle.

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Figure 1. Bereaved families' experiences about suctioning for death rattle.

Figure Legends: Percentage of the bereaved families with 4 or more agreements on 5-point likert scale.