Original Article

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

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Abstract

Context. Bereaved family members witnessing a patient's death rattle often experience distress. However, the benefits of specific care measures aimed at decreasing death rattle-associated family distress have not yet been evaluated.

Objectives. To clarify death rattle-related emotional distress levels among family members and their perceptions of the need for death rattle care improvement and explore the factors influencing both these issues.

Methods. A cross-sectional questionnaire survey of bereaved family members of cancer patients was conducted in 95 palliative care units in June 2007.

Results. Six hundred sixty-three questionnaires were mailed out, and 390 (61%) responses were analyzed. Among these, 181 (46%) respondents experienced death rattle. Of these, 66% reported high distress levels and 53% perceived a strong need for improved death rattle care. Factors influencing high distress levels were the gender (female) of family members, unawareness about death rattle being a natural phenomenon, and their fear and distressing interpretations of death rattle. Factors influencing perceptions of a strong need for improved care were the gender (male) of family members, severity of death rattle, death rattle-associated discomfort to patients, family members' experiences of inadequate nursing care (e.g., repositioning) and insufficient consultation about suctioning, and their perception of uncomfortable smells.

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Conclusion. To decrease family-perceived distress, medical staff should alleviate patient symptoms and suffering with a comprehensive care strategy, try to decrease uncomfortable smells, and communicate with family members to address distressing interpretations and fears. J Pain Symptom Manage 2014;48:2–12.

Key Words
Death rattle, respiratory sounds, neoplasm, terminal care

Introduction

Death rattle caused by tracheal secretion in the absence of a functioning cough reflex is a common symptom reported in 23%–92%[1–5] of dying patients and witnessed by 41%–44% of family members.[2,3] In a quantitative study, 78% of family members who witnessed this symptom reported high distress levels.[6] Along with pain and agitation, it ranks among the most common symptoms in the last 48 hours of life.[7] Because of decreased consciousness levels, dying patients are not aware of this involuntary sound and are unlikely to feel the associated discomfort.[8] Therefore, alleviation should aim at decreasing family members' distress.

A previous qualitative study demonstrated that family members interpret death rattle in various ways,[9,10] with those disturbed by the sound making more distressing interpretations.[10] However, family members' experiences, perceptions, feelings, and interpretations about death rattle remain unclear.

Common treatments for death rattle include patient repositioning, nasopharyngeal/oropharyngeal suctioning, and anticholinergic drug therapy to inhibit secretions.[11] Wee et al.[10] suggested that effective communication with medical staff about the symptom, causes, and treatments is helpful to alleviate family members' concerns and suppress unwarranted fears. However, the benefits of these interventions have not been evaluated, although numerous studies have assessed the effectiveness of anticholinergic drugs.[4,5,12–16] The effectiveness of anticholinergic drugs for family members was reported, although family-perceived distress was not.[13] Effective measures to decrease family-perceived distress, therefore, must be identified and assessed.

In this cross-sectional study, we clarified emotional distress levels of bereaved family members and their perceptions of the need for improved care. We also explored factors influencing these perceptions.

Methods

We administered a cross-sectional questionnaire to bereaved family members of cancer patients as part of the Japan HOspice and Palliative Care Evaluation Study (J-HOPE study), a national survey conducted in Japan in June 2007.[17]

Participants and Procedure

We asked all the 153 palliative care units (PCUs) approved by Hospice Palliative Care Japan before September 2005 to participate in the J-HOPE study. Of these, 103 PCUs responded, but three were rejected by the institutional review board; a total of 100 (65%) PCUs participated. To find potential participants, we asked each institution to identify bereaved family members of cancer patients who died between November 2004 and October 2006 (up to 80 participants at each institution). Inclusion criteria were as follows: death in a PCU, aged ≥20 years, and age of the family member ≥20 years. Participants without a permanent address, those with serious psychological distress as determined by the primary physician, and those unable to complete a self-report questionnaire were excluded. Accordingly, 8508 potential participants were identified; 553 were excluded, and we sent questionnaires to 7955 participants. The questionnaires comprised two sections: common questionnaires and 12 additional questionnaires, one of which was the questionnaire of this study. Additional questionnaires were randomly assigned to these 7955 participants. Further details of the J-HOPE study have been highlighted previously.[17]