

Family-Perceived Distress From Delirium-Related Symptoms of Terminally Ill Cancer Patients

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Delirium is a frequent symptom of terminally ill cancer patients and can cause serious distress to family members. To clarify the degree of emotional distress of family members concerning terminal delirium, a survey of bereaved families was performed. A questionnaire was mailed to 300 bereaved families with a request to rate the frequency and level of their distress for 12 delirium-related symptoms. A total of 195 responses were analyzed (effective response rate = 65%). Seventy-four percent and 62% of the family members reported that the patients had symptoms of physical restlessness and mood lability, respectively. Psychotic symptoms, such as hallucinations and delusions, were reported by 35%–37%, and somnolence was reported in 92%. The prevalence of cognitive symptoms (e.g., communication difficulty, memory disturbance) ranged between 50% and 72%. More than two-thirds of the bereaved family members perceived all delirium-related symptoms other than somnolence as distressing or very distressing when they occurred “often” or “very often.” For physical restlessness, mood lability, and psychotic symptoms that occurred “sometimes,” 27%–36% of the family members had moderate to high levels of distress. The bereaved family members of terminally ill cancer patients experienced high levels of distress from both the agitation and cognitive symptoms of terminal delirium. Multidisciplinary interventions, including the prevention of agitation and the minimization of cognitive impairment, pharmacological or medical treatments, and supportive and psychoeducational approaches for family members, are needed to alleviate family distress. (Psychosomatics 2004; 45:107–113)

Delirium or cognitive disorders occur in 68%–90% of terminally ill cancer patients just before their death.^{1–6} Although cognitive impairment can sometimes be labeled as part of the “natural” dying process, delirium-related symptoms can cause great distress in both patients and family members.^{7–11} Since one of the primary goals of integrated palliative care is to alleviate family suffering, active support for the family members of delirious terminal patients is important. However, to our knowledge, only one pioneer study¹² has addressed the potential impact of delirious symptoms on family experiences in a cancer care setting. This prospective observation study of 75 family members of delirious cancer patients revealed that 76% of

the family members showed high levels of psychological distress when their family members had delirium symptoms. However, since these study subjects were limited to patients who consulted a psychiatric service and recovered from delirium, these findings cannot be generalized to family members who experienced terminal delirium. Also,

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Distress From Delirium-Related Symptoms

since family distress was evaluated with only a single numeric scale to measure overall distress, we cannot determine which symptoms the family members perceived as more or less distressing. Since understanding family distress with terminal delirium is valuable in developing effective care strategies, we performed a nationwide survey of bereaved families to identify the degree of family distress experienced with each delirium-related symptom.

METHOD

This was part of a large nationwide mailed survey that investigated bereaved families' evaluation of specialized inpatient palliative care services in Japan. In the second part of the questionnaire, the respondents were asked to report the frequencies and levels of their distress concerning each delirium-related symptom.

Of 82 palliative care units approved as formal members of the Japanese Association of Hospice and Palliative Care Units by the end of 2000, 70 institutions agreed to participate in this survey. Before the survey was conducted, a letter explaining the aims and methods of the study was mailed to 3,097 potential participants (93% of all deaths) with a request to return an enclosed informed consent form. The inclusion criteria for the potential participants were the following: 1) bereaved family members who had lost a patient at one of the participating palliative care units, 2) ages 20 or older, 3) capable of replying to a self-report questionnaire, and 4) no serious psychological distress, as identified by the responsible physicians. Of 3,097 potential participants, 1,184 (38%) returned the written informed consent. We then randomly divided this total group into three groups to perform three different questionnaire surveys. This survey was performed in June 2002 with 300 consenting participants as one of the three divided groups. The ethical and scientific validity were confirmed by the institutional review boards of each hospital.

Questionnaire

The questionnaire (available from the first author) was developed by the study group. The bereaved subjects provided data for sociodemographic characteristics: gender, age, relationship to the deceased, time since patient death, and frequency of visiting the patient in the last week of life. Patient gender and age were collected from medical charts.

The respondents were requested to rate the frequency of 12 delirium-related symptoms (insomnia, somnolence,

memory disturbance, thinking difficulty, communication difficulty, disorientation, irrelevant/incoherent speech, hallucinations, delusions, physical restlessness, inappropriate behavior, and mood lability) during the last week of life on a 4-point scale of "not at all," "sometimes," "often," and "very often." These symptoms were selected on the basis of the Memorial Delirium Assessment Scale (Japanese version), the Delirium Rating Scale, and interviews with palliative care nurses and bereaved family members to cover a broad aspect of delirium.¹³⁻¹⁵ Moreover, the respondents were requested to rate the levels of their distress for each delirium-related symptom on a 5-point scale of "not distressed at all," "not so distressed," "slightly distressed," "distressed," and "very distressed."

The medical terms were paraphrased in the questionnaire so that lay respondents could understand them. The face validity and acceptability of the questionnaire were confirmed by a pilot test on 50 bereaved family members.

Analyses

To make interpretation of the results easy, we clustered the responses about family-perceived distress by multidimensional scaling analysis based on the Euclidean distance model of the stimulus configuration of measures. This statistical method can visualize endorsement similarities by constructing a matrix of correlation coefficients. Kruskal's stress values were used as a measurement of the lack of goodness of fit, and the two-dimensional solution was adopted because of its simplicity, ease of interpretation, and minimum improvement of stress and percent variance accounted for in the three-dimensional solution.

Figure 1 shows the structure of family-perceived distress regarding patients with terminal delirium. We identified four interpretable groups: 1) physical restlessness; 2) mood lability and insomnia; 3) psychotic symptoms, including hallucinations, delusions, and inappropriate behavior; and 4) cognitive symptoms, including somnolence, communication difficulty, memory disturbance, thinking difficulty, disorientation, and irrelevant/incoherent speech. We adopted this model because of good clinical validity, as agreed on by the authors, and consistency with previous findings that neurobehavioral, psychotic, and cognitive symptoms were identified as the underlying structure of the Memorial Delirium Assessment Scale and the Delirium Rating Scale.^{14,15} All analyses were performed with the Statistical Package for the Social Sciences (version 9.0).

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