

Journal Watch

Terminal Delirium Recommendations from Bereaved Families Experiences

Reference: [Morita T](#), [Akechi T](#), [Ikenaga M](#), [Inoue S](#), [Kohara H](#), [Matsubara T](#), [Matsuo N](#), [Namba M](#), [Shinjo T](#), [Tani K](#), [Uchitomi Y](#), *Journal of Pain and Symptom Management*, 2007 Dec;34(6): 579-89

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Abstract:

BACKGROUND: Although delirium is a common complication in terminally ill cancer patients and can cause considerable distress to family members, little is known about the actual experience of family members. The primary aims of this study were thus to explore: (1) what the family members of terminally ill cancer patients with delirium actually experienced, (2) how they felt, (3) how they perceived delirium and (4) what support they desired from medical staff. **METHODS:** A single-center in-depth qualitative study on 20 bereaved family members of cancer patients who developed delirium during the last two weeks before death. Content analysis of transcribed text was performed. **RESULTS:** Families experienced various events including other than psychiatric symptoms, such as ;patients talked about events that actually occurred in the past', ;patients were distressed as they noticed that they were talking strangely,' ;patients talked about uncompleted life tasks', and ;patients expressed physiologic desires such as excretion and thirst'. Family emotions were positive, neutral, or negative (eg, distress, guilt, anxiety and worry, difficulty coping with delirium, helplessness, exhaustion and feeling a burden on others). Families perceived the delirium to have different meanings, including positive meanings (eg, relief from real suffering), a part of the dying process, and misunderstanding of the causes of delirium (effects of drugs, mental weakness and pain). Families recommended several support measures specifically for delirium, in addition to information and general support: ;respect the patients' subjective world', ;treating patients as the same person as before', ;facilitating preparations for the patients' death', and ;relieving family's physical and psychological burden'. **CONCLUSIONS:** From the results of this study, we generated a potentially useful care strategy for terminal delirium: respect the patients' subjective world, treat patients as the same persons as before, explore unmet physiological needs behind delirium symptoms, consider ambivalent emotions when using psychotropics, coordinate care to achieve meaningful communication according to changes in consciousness levels during the day, facilitate preparations for the patients' death, alleviate the feelings of being a burden on others, relieve family's physical and psychological burden and information support.

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Summary:

The aim of the study was to:

1. Clarify the distress levels of bereaved families and their perceived necessity of care related to terminal delirium
2. Explore the association between these levels and family-reported professional care practice, family reported patient behavior; and their interpretation of the causes of delirium

Method:

Questionnaire mailed to bereaved families

Subjects were identified by primary palliative care physicians following inclusion criteria

Each participating hospital would enroll 90 consecutive families of patients who had developed delirium

Endpoints:

Family perceived emotional distress related to terminal delirium and the necessity for improvement in professional care at that time

Strengths:

1. Sample size and response rate of 70%
2. Excluded patients with preexisting symptomatic organic brain pathology

Weakness:

1. Retrospective study
2. Some families denied the episode of delirium
3. As all patients received specialized palliative care, adherence to recommended practiced care ,was high

Relevance to palliative care:

Delirium occurs in terminally ill patients as frequently as 90% , causing distress for the families. This study has demonstrated some of the factors contributing to family stress during the terminal period of illness. This result demonstrates that being with families of delirious patients is an essential element of care at this stage of the illness.