



PALLIATIVE CARE CASE OF THE MONTH

“Delirium: Patient and Caregivers Experience”

by

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Case: Case #1: The patient is a 62-year-old man with no past medical history until six months ago when he was diagnosed with lung cancer. He was recently admitted to the hospital with a bone crisis and hypercalcemia. During his hospitalization he became quite withdrawn and paranoid telling the family that the nurses were out to “get him.” The family was confused; they reported that sometimes he seemed like he was normal but other times he did seem confused, and that made them worry that something was actually happening. He also talked to the family about wanting to die which also distressed them as he had said he was willing to go through the chemotherapy. As his delirium resolved, he reported that the experience was distressing. He said that he had visual hallucinations, knew he was confused but could not talk about it and felt that things were just “not right”.

Case #2: The patient is a 75-year-old man who was admitted with a long history of COPD, osteoporosis, and coronary artery disease. Two days before admission he developed a cough and in the emergency room was found to have a right lower lobe pneumonia. He was admitted to the ICU where he was intubated. On hospital day three he was extubated, made DNR/DNI and sent to the floor. That evening he developed respiratory distress after aspirating, became delirious and began to talk, in graphic terms, about his wife having an affair with his friends. Over the next 48 hours he was quite agitated, cursing, and talking about his wife’s illicit behavior. The patient’s wife was devastated trying to reassure the patient that nothing happened and wondering why her church-going husband had changed so much. The clinicians, after long conversations with the family, decided to sedate him, and he died a day later.

Discussion: Delirium is a common syndrome with occurrence rates of up to 70% in medical intensive care units, 28% following hip fractures, and 20-40% of generalized medical inpatients.⁽¹⁾ There are numerous articles about the short and long-term adverse effects of delirium: that it is associated with higher short-term mortality and hospital complications; that its cognitive effects may extend long after hospitalization, and even months after discharge is associated with higher mortality and institutionalization.⁽²⁾ Less-well described are patient and caregiver’s experiences and recollection of the experience or longer-term psychological morbidity. This review will focus on those issues.

1. Do patients recall their delirious episodes? The data here is quite variable. Some studies report the portions of patients that recollect factual events while others talk about patients who recall being confused, dreaming or delusional memories. The range of patients who report dream-like or delusional recollection both in the ICU and on the floor range somewhere between 20-75%. Studies which have looked at the content of what is recalled reveal several themes. These include feelings of disorientation and unreality, lack of control, misperceptions, hallucinations and delirium.⁽³⁾

2. Do patients find delirious episodes distressing? The meager data suggests the answer is yes. A study of hospitalized cancer patients found that of the 54% of patients who recalled delirium, 80 reported it was severely distressing. Interestingly, the rates of distress were no different in hypoactive versus hyperactive delirium. The only predictor of the severity of distress was the presence of delusions.^(4,5) The relationship of the short-term distress and longer-term psychological or psychiatric morbidity is not well understood. While ICU delirium and PTSD (post-traumatic stress disorder) were not correlated, patients who suffered delirium after a stem cell transplant displayed greater symptoms of depression and anxiety. This finding was confirmed in a literature review, although the causal relationship is unclear.⁽³⁾

3. What effect does delirium have on the patient’s relatives? Only a few studies have analyzed this in a rigorous way. One qualitative study found that 70% of families expressed distress at observing delirium in their relatives; typical reported as guilt, anxiety, worry, hopelessness, and exhaustion.⁽⁶⁾ Studies that have quantified the level of distress have found that caregiver’s ratings are even higher than the distress that patient’s report (3.75 on a 4.0 scale compared to 3.2).⁽⁵⁾ Symptoms that were particularly reported as distressing were physical restlessness, mood lability, and psychotic symptoms. In one study more than two-thirds of family members found all delirium related symptoms other than somnolence as distressing or very distressing.⁽⁷⁾ In a study of 200 caregivers of patients with cancer, caregiver-perceived delirium was associated with a 12x increase in generalized anxiety, even after controlling for caregiver burden and exposure to other stressful patient experiences, suggesting a longer-term impact on caregivers.⁽⁸⁾

4. What can be done to help? The majority of interventions for patients are in the ICU. In one study, diaries which summarize the patient’s stay and are read by the patient once they have recovered, have been shown to decrease PTSD.⁽⁹⁾ Similar debriefing is recommended for delirium but has not been studied. Other studies have looked at providing information to patients about the possibility of delirium prior to the episode. The qualitative data is positive but this has not been studied in a rigorous way.⁽³⁾

The majority of studies for families have been done in terminal delirium and what can be done to help the caregivers. A multicenter survey of over 150 families found they recommended “being present with the family, respecting the patient’s subjective world, explaining the expected course with daily changes, and relieving the family-care burden.”⁽¹⁰⁾ Other studies have found that caregivers have found a leaflet about delirium as has helped them understand the patient’s physical condition better, understanding what they could do for the patient and preparing for the patient’s death.⁽¹¹⁾ No data has evaluated an intervention’s impact on caregiver’s distress or psychological outcomes.

Personal details in the case published have been altered to protect patient privacy.

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Resolution of Case: There is no evidence-based data for what is most helpful to families who are shocked to see their loved one who acts so differently than normal (Case #2). It is even more disturbing because the patient otherwise looks “normal” and thus, it is hard for the family to understand why sometimes he is normal and other times “different.” In my experience, it sometimes helps to perform the Confusion Assessment Method in front of the family so they can see that, despite their loved one seeming cognitively intact, they are having trouble with basic cognitive tasks. Talking to the family about how the patient’s brain is “not working” because of the serious illness may be helpful. Finally, most experts suggest not continually correcting the patient; instead the family can simply respect the patient’s experience and provide a loving presence.

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