


10-2003

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## ScholarWorks Citation

McCurren, Cynthia and Cronin, Sherill Nones, "Delirium: Elders Tell Their Stories and Guide Nursing Practice" (2003). *Peer Reviewed Articles*. 40.  
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## Delirium: Elders Tell Their Stories and Guide Nursing Practice

*Delirium is one of the most serious and prevalent cognitive disorders among hospitalized elders. Fourteen elders participated in this phenomenologic study describing the "lived experience" of delirium from the patient's perspective. Implications for nursing practice are derived from their reality and insight.*

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**Acknowledgments:** This study was supported in part by funding from the Lifespan Forum, Louisville, KY. The following are acknowledged for their assistance with this project: Beverley Holland, RhD, ARNP; Deborah Strotman, MSN, ARNP; Cathy Bays, PhD, RN; and Cheryl Zambroski, PhD, RN.

**M**rs. D. was an 80-year-old widow who remained actively involved with her family, church, and volunteering. She was very aware of the need to negotiate her basement stairs carefully; however, she fell down the stairs one morning and found herself in incredible pain and unable to get up. She could hear her phone ringing persistently during the next several hours, and was quite frustrated at her inability to get up and seek help for herself. After many phone calls were unanswered, her daughter came to the house. The next several hours were filled with an ambulance trip to the hospital, time in the ER, and eventual surgical repair of a fractured hip. Over the next 48 hours, Mrs. D. became increasingly confused as to time and place. She fearfully questioned caregiving attempts, tried repeatedly to get out of bed, and cried out to people who were not even in the room. The daughter told the nurses that Mrs. D.'s mother had suffered from dementia and questioned if her mother was also experiencing dementia. One nurse concurred that most old people are demented, and that they make for very challenging patients. Another nurse advised Mrs. D.'s daughter to stay with her mother because "she certainly did not have time to deal with Mrs. D.'s behavior when she was responsible for 8 other patients."

If this scenario seems familiar, it is because similar events occur daily across the nation in numerous health care facilities. Mrs. D. was suffering from acute confusion or delirium, one of the most serious and prevalent cognitive disorders among hospitalized elders.

### Background and Significance

*Acute confusion* (AC) and *delirium* are used interchangeably by most health care professionals, with nurses tending to favor the use of acute confusion and physicians using the term delirium. Both terms refer to the same phenomenon characterized by the American Psychiatric Association (1994, p. 129) as a disturbance of consciousness with reduced ability to focus, sustain, or shift attention; a change in cognition; or the development of a perceptual disturbance. These occur over a short period of time and tend to fluctuate over the course of the day. The three variants of delirium are *hyperactive delirium* (such as psychomotor hyperactivity, marked excitability, hallucinations); *hypoactive delirium* (such as lethargy, decreased awareness/alertness, apathy); and *mixed delirium*

involving behavior that fluctuates between the hyperactive and hypoactive variants (Foreman, Wakefield, Culp, & Milisen, 2001).

Delirium can be differentiated from dementia, which is a degenerative process producing structural changes in the brain tissue. The cognitive impairment of delirium has a sudden onset, and is transient and potentially reversible; dementia has a gradual onset and is irreversible (Rapp et al., 2000). The etiology of delirium is complex, dynamic, and multifactorial. The patients at highest risk are older adults who have impaired ability to adapt to physiologic alterations (such as hemodynamic or metabolic instability, dehydration, infection, hypoxia); environmental stressors (such as sensory overload, relocation, sleep deprivation); and pharmacologic agents (such as sedatives, hypnotics, anticholinergics) (Foreman et al., 2001; Rapp et al., 2000; Roberts, 2001).

Delirium is a prevalent disorder among hospitalized elders, with incidences reported as high as 80% (Foreman et al., 2001; Pompei et al., 1994). Each year, delirium complicates and prolongs hospital stays for more than 2.3 million older adult patients. It involves more than 17.5 million inpatient days and accounts for more than \$4 billion of Medicare costs (Foreman et al., 2001; Inouye et al., 1999). Patients with delirium have higher mortality rates and are more likely to experience nursing home placement (Rapp, 2001). They are unable to care for themselves and exhibit behaviors that are unsafe, requiring more nursing time (Foreman et al., 2001).

Increased attention to this phenomenon has been noted in the literature and in research over the last 2 decades; a MEDLINE search revealed 1,530 related citations from 1983 to 2001. Considerable effort has been put forth to create instruments to aid in detecting this phenomenon. Suggestions for interventions and management have been reported (Foreman & Zane, 1996; Roberts, 2001). Despite all this, delirium is still relatively neglected as a routine clinical focus in older adults.

Brief mental status tests such as the Mini-Mental State Exam (MMSE) (Folstein, Folstein, & McHugh, 1975) and the short Portable Mental Status Questionnaire (Pfeiffer, 1975) have been developed for cognitive screening. These tests contain questions to evaluate orientation, memory, attention, abstract thinking, and/or other dynamics of language. The chief advantage of mental status tests is that they provide standardized and systematic assessment methods for data collection and interpretation. They usually are also sensitive enough to detect moderate-to-severe instances of delirium. Their limitations include significant false-negative rates as high as 50% (Nelson, Fogel, & Faust, 1986); they do not assess features specific to acute confusional states, and they are not suitable for retesting (Neelon, Champagne, Carlson, & Funk, 1996).

Other individuals have attempted to create criteria or checklists to use for detecting AC/delirium. Examples include the DSM-IV guidelines for diagnosing delirium (APA, 1994), the Delirium Symptom Interview (Albert et al., 1992), and the Clinical Assessment of Confusion (Vermeersch, 1990). Investigators using these instruments to compare acutely confused versus nonconfused groups have often attempted to identify the cognitive and behavioral nature of delirium. Generally, they have had limited success in explaining the variance or identifying the variables that predict the development of acute confusion (Foreman, 1991).

Lack of recognition of AC/delirium by health care providers is a potential problem. Many physicians and nurses fail to identify cognitive disorders, with undetected cases ranging from 16% to 72% (Gehi, Strain, Wiltz, & Jacobs, 1980; Palmateer & McCartney, 1985; Souder & O'Sullivan, 2000). Failure to identify confusion can be attributed to a number of factors, including:

- Lack of knowledge about what behaviors or cognitive aspects to assess (Berkowitz, 1981; Morency, Levkoff, & Dick, 1994).

- Failure to recognize the physiological significance of AC/delirium and the potential impact on the patient's physical and emotional well-being (Eden & Foreman, 1996).
- Failure to use a routine, standardized, and comprehensive cognitive assessment (Johnson, 1999).
- Disinterest in or stereotyping of the confused elder (Batt, 1989).
- Limited interactions with patients (Eden & Foreman, 1996).

Equally alarming are diagnostic errors. It is not uncommon for elders to be labeled as *demented* when they are actually experiencing delirium, supported by an error rate of 37% in one study (Hoffman, 1982) and qualitative study results in another (Fick & Foreman, 2000). Misdiagnosis of delirium as dementia or depression results in inappropriate treatment (Foreman et al., 2001). Failure to treat delirium can lead to negative outcomes previously cited.

## Purpose

Is there a way to heighten awareness about the problem of delirium among elders to the point that all health care providers will automatically assess for it in any hospitalized older adult patient? Can health care providers understand the impact that an experience of delirium has on an individual and be motivated to be more sensitive and caring to the patient who is often labeled as "annoying" and "troublesome?" The authors of this study were challenged by these questions and theorized that allowing individuals who had actually experienced delirium to tell their stories would be a poignant way to heighten awareness among health care providers. In addition, analyzing the personal experiences of delirium could aid in the continued effort to accurately operationalize the construct of delirium and improve methods of detection. The purpose of this study was to describe the phenomenon of delirium based on the lived experience of hospitalized elders.

## Methods

A phenomenologic approach was used for this descriptive study. The focus of phenomenologic inquiry is on *what* people experience and *how* they interpret and give meaning to those experiences (Streubert & Carpenter, 1999). Describing the "lived experience" of delirium from the patient's perspective helps health care providers understand the patterns in this phenomenon, which may lead to improved methods of detection and intervention. The phenomenologic approach is based on the assumption that "there is something in the nature of human experience beyond sheer reason or sensory observation which produces knowledge" (Davis, 1978, p. 194).

A purposive sample of 14 hospitalized elders ( $\geq 60$  years of age) was selected from medical-surgical units in a 442-bed acute care hospital located in the Southeast. Subjects were chosen if they had a documented delirium experience which they could recall in detail, at least in part. Patients were excluded from the study if they were unable to hear, unable to speak or understand English, or had a confirmed diagnosis of dementia. The final sample consisted of 10 men and 4 women who ranged in age from 65 to 88 years, with a mean of 75.2 years. Of the sample participants, 11 elders had disorders that were cardiovascular in nature, 2 had renal conditions, and 1 had pulmonary disease.

Institutional review board approval was obtained prior to the start of the study. Prospective participants were identified through consultation with the nursing staff on selected units of the hospital. Delirium was confirmed based on review of the medical record, a precise history obtained from significant others who could confirm the acute and sudden decline in the person's usual cognitive state, and administration of the MMSE. Subjects were approached regarding participation in the study once the delirium had cleared and their amount of recall could be determined.

Demographic data were

obtained from individuals who agreed to participate in the study and signed informed consent. The interviews took place in the subjects' hospital rooms if the delirium cleared prior to hospital discharge, or in their homes after discharge if necessary. Interviews were guided by three focusing statements:

- Think about when you first became ill or were first hospitalized. Describe any changes you were aware of with regard to your ability to think clearly.
- As your illness progressed, you did not behave in your usual manner. Describe what you remember about this time.
- What helped you during this time?

The interviews were tape recorded and transcribed verbatim. Data were analyzed according to guidelines by Colaizzi (1978). The ongoing review was essential to assess for the occurrence of saturation and the emergence of a universal, consistent pattern. Analysis began with both investigators independently reading all of the interview transcripts in their entirety in order to gain an overall impression from them. Each transcript was then read again and significant statements were extracted. Formulated meanings were developed for each of the statements, which were then aggregated into clusters of themes. Each of the theme clusters was validated against the original transcripts. Finally, an exhaustive description of the confusion experience was developed.

To enhance the credibility of the data, a peer debriefer was used to provide an external check on the inquiry process (Lincoln & Guba, 1985). The peer debriefer was external to the research project, but knowledgeable about the area of inquiry and the phenomenologic method. This individual reviewed all transcripts and interpreted meanings, probed the investigators' biases, and clarified the basis for the interpretations. To address the confirmability of the data, an inquiry auditor was used as well. This second independent auditor examined the

process of the study's conduct (audit trail), the data, the field notes, the findings, and the interpretations. This individual attested that the inquiry was internally coherent and that the interpretations were supported by the data.

## Results

Three clusters of themes resulted from the analysis: (a) *being in* the confusion event; (b) *responding to* the confusion; and (c) *dealing with* the confusion. Being in the confusion consisted of the themes of awareness, fuzziness, and altered time and place reality. Responding to the confusion consisted of the emotions elicited by the event and included fear, anxiety, anger, and embarrassment, among others. Dealing with confusion consisted of the elders' attempts to cope with the situation, the family or significant others' reactions, and the nursing staff's interventions.

### Being in the Confusion

Awareness of the confusion event occurred along a continuum, with some individuals perceiving the confusion as reality and others very aware of the fact that they "weren't right." Those individuals who were unaware of their confusion at the time could, in retrospect, remember how real it all seemed. One man noted, "I thought I was thinking clearly...I felt that I had all my faculties around me the whole time." Another man who had experienced visual hallucinations recalled, "Just as clear as day I could see them [people in his room]. I could see them clearer than I can see today. They were there — physical." Other individuals reported that they realized at the time that they were confused but were unable to do anything about it. One man said, "We would be sitting there talking about this and I'd start talking about something else and I would think, 'Well, that is not related to what we are talking about!' [For example], we were sitting there talking about hunting mushrooms and suddenly I start talking about cassette recorders. And you know and I know, what does that have to do

with mushrooms?...and I couldn't control myself." One woman was not only aware of her confusion, but would attempt to hide it during her interactions with others. "It was very important to me that I should not appear dumb — [when asked a question] I would stall and be clever. I knew I was confused. I knew that."

"Fuzziness" was a commonly described characteristic of confusion. Most subjects reported experiencing a dream-like, "other world" state, where reality blended with illusion. As one woman noted, "It made me feel like I was in another land, so to speak; in another place, another reality. It was like I was in a dream and knew I was dreaming and when I would wake up, I knew I was dreaming...it was just confusing. I felt that I was like in a dream but I was aware and I was awake at the same time." Another man described it, "I would come to some sort of a wake-up — I don't know what it was, the twilight zone or something."

For some subjects, this haziness involved experiencing dissociation between auditory and visual cues. As they drifted in and out of awareness, they would hear voices that were disconnected from reality. One subject described it as, "sort of like someone had pulled a curtain." Another described talking with someone, and "by the time I got through with the answer, the person was gone. It was just 'pffft,' they were gone." One woman gave this example: "I've got five girls [her children] and I couldn't distinguish one from the other. I knew that they were my daughters; I knew each one of them by their voice. Well, I guess I didn't see them and yet I did see them and that was a bit of confusion...I guess in my mind I was saying I could see how much they look alike, but yet I couldn't see and that was strange."

In several instances, the subjects' fuzziness took the form of hallucinations. One subject reported seeing termites on the wall, followed by mice on her bed, "two of

them sitting up in the corner and two little ones was playing underneath of where the pillow was." Another subject saw a ladder which he "climbed" and, at another time, a boat which he attempted to board.

***Some subjects' confusion with what was happening caused them to become paranoid and lose trust in others.***

However, more subjects reported thought disturbances that appeared to be illusory in nature (such as misinterpretations of real sensory experiences). For example, one woman reacted to physician rounds: "I thought there were some photographers and things around, and they were taking advantage of people...photographing them when they shouldn't have been." Other subjects appeared to have illusions regarding instances of being transported. One man believed he had been taken out and put "in this bus, then...we were partly in the parade. They had special dump trucks so they wouldn't get messed up in the mud and stuff in the street, and I couldn't believe that they went through all this goddamn trouble for this parade." Another recalled being placed on a stretcher and taken "out to a field...and I watched a soccer match and hockey or something. [Afterwards] we came back around and [over him] there was a clear plastic-like roof. And it wasn't raining on me, but there was moisture on the roof."

Alterations in time and place reality were common, an experience one woman described as, "It was like I was gone for awhile." Time passage was distorted, with subjects thinking elapsed hours were days, and confusing nighttime and daytime. Keeping track of the date was difficult for them. Many of the subjects were also uncertain about where they were. When told he was in the hospital, one man responded, "How can I be in [the hospital] when I'm down here in the basement of this building?" Another said that he kept

insisting he was not in the hospital, but someplace else. Another admitted, "I didn't know where I was or what was going on!"

The confusion experience evoked a range of negative emotions for the subjects. Many expressed feelings of fear and anxiety. As one woman noted, "Oh, it was a terrible experience — groping, trying to get it all together, and internalize it, but I couldn't do it...I was frightened and just really uncomfortable."

The anxiety produced by this frightening experience, coupled with misinterpretation of events going on around them, led many subjects to become angry and frustrated. One man noted, "I was confused to the point that I told my wife, 'I'm angry at you, I'm angry at my children,' because nobody came to my rescue." Another angrily blamed his daughter for his being restrained, "It's your fault that they got me tied down...because you are the one who had them to do it." As one man expressed, "Talk about confused — boy, you're confused. It didn't annoy anybody but me, but I'll tell you it's frustrating."

Some subjects' confusion with what was happening caused them to become paranoid and lose trust in others. Several people reported that they thought the hospital staff was plotting against them. One man believed that he was the target of a plot "to collect body parts from people," while another thought there were people "taking advantage of [patients], photographing them when they shouldn't have been." One subject said, "I had led myself to believe that there was a conspiracy between some of the hospital staff and someone in charge of operations, and they were pulling the wool over my eyes." Retrospectively, some subjects also felt embarrassed about things they had said and done while confused. As one man noted, "Of course it bothers me. I'm not that type of person [acting like an 'ass'], and I never have been."

## Dealing with the Confusion

*Dealing with confusion* encompassed the responses of family and significant others, staff, and the patients themselves. When asked about things that helped them during their episodes of confusion, subjects identified contact with their loved ones, explanations, and frequent reassurance as the most beneficial. One woman noted, "My family members kept talking to me...and the more they talked, I thanked the Lord that I shook off the state of confusion." Explanations from nurses about what was happening and why helped to reassure both patients and their families.

Subjects also identified nursing behaviors that were not helpful. Several mentioned not receiving explanations for what they were experiencing. One said, "I had nobody to talk to or explain to me what was going on. And they never did explain to me!" They also lamented nurses who seemed to avoid their questions or appeared to have no time for them. One mentioned a nurse who responded to his call bell, "What is it this time?" I remember that 'why are you wasting my time'-like attitude." Another subject's daughter noted that the nurses seemed irritated if she would respond to his questions and suggested that she "change the subject." But as she explained, "If you don't know what he is frightened of, how are you gonna cope with whatever it is he is going through?" One subject also cautioned nurses to be aware of how the comments may be misinterpreted. He noted, "One of them said something like, 'What do you think we are doing to you, Mr. H.?' It was kind of like a suggestion...and I was thinking, 'Yeah, what are they doing to me?' and that's when [the conspiracy idea] started working on me."

In their descriptions, subjects also revealed ways in which they were attempting personally to cope with their confusion experience. The comments of some suggested that they had been reflecting on the experience in an attempt to understand it. One woman noted, "All kind of crazy

stuff was going on...and now I realize that all of it was nonsense and didn't make sense." Another said, "I'm still trying to figure out what I was trying to do, if that makes any sense." However, others seemed to be trying to forget the whole experience. As one woman explained, "They tell me it happened, and I assume that it did, but I don't recall. I have no particular memory about it because I paid no attention to remember."

## Implications for Practice

The study's findings help to explain in part the clinical variations in the picture of the confused patient noted in the literature (Foreman et al., 2001). Patients who experience hallucinations or paranoia are likely to become agitated and excitable. Patients who are aware of their (decreased) mental acuity may try to hide their condition from others, responding in more docile and socially acceptable ways. The nurse should consider these variations when assessing the at-risk patient. They point to the need to probe quick responses to assessment questions which may reflect patients' attempts to cover up their current state.

The descriptions of the lived experience of delirium are rich with insight, and must be considered in the context of the typical workday for a nurse. The nurse may be troubled by the patient who strikes out with insults or violence, insists on believing that people or objects are present in a room when clearly they are not, calls frequently for needs stemming from fear or anxiety, or is disruptively paranoid. In the current work environment, the confused patient can strain the coping abilities of the stressed nurse. The stories told by the patients offer nursing care strategies that are relatively simple to implement. They also affirm findings from two similar studies by Laitinen (1996) and Schofield (1997) suggesting patterns of behavior that should be monitored and evaluated.

The need for explanations and therapeutic communication was clearly demonstrated by

patients in this study. Anticipatory explanations might be particularly useful for surgical patients and their families. By discussing possible sensory-cognitive alterations that may occur postoperatively, the nurse can help the patient and family avoid panic. Previous work using this strategy revealed that cardiac-surgical patients who had been educated about possible postoperative confusion did not suffer from delirium as frequently as those who did not receive the education (Segatore, Dutkiewicz, & Adams, 1998). A prior understanding of the event may be the key to eliminating or reducing the impact of delirium.

One subject suggested that the nurse should be aware of comments or actions that may be perceived as threatening. When patients are surrounded by misinterpretation and feeling the need to defend themselves in their unreal world, there is a great deal of insecurity. In the nurse's rush to "get the tasks done," with a focus on a personal agenda, a sense that the nurse is annoyed, angry, or impatient may be perceived by the patient. If the patient is feeling insecure, he/she may act out in self-defense. While it is difficult to have a caring relationship in the middle of chaos and confusion, the nurse must consider the importance of a trustful and caring relationship. Even though time limitations may be considered a barrier to this notion, every moment of time spent with a patient is an opportunity to be truly present. Laitinen (1996) summarizes the concept of *true presence* (Parse, 1981) as a special way of being with a person that recognizes the other's value as a human being. It incorporates the familiar phrase, "walk a mile in my shoes." Laitinen (1996) suggests that by being truly present in the patient's confused world, the nurse can give the patient reassurance that he or she is safe, understood, and accepted.

Sensory or verbal experiences that are real are often misinterpreted by the confused patient. The astute nurse can evaluate the environment or cir-

cumstances of the patient's hospitalization and may determine the cause of the misinterpretation. For example, when the one patient in this study perceived that photographers were taking advantage of patients and taking pictures when they should not have been, it was important to consider what created this perception. In this case, it appeared to be linked to physician rounds. This was an opportunity for a simple explanation to the patient, preparation prior to physicians coming to the bedside, and reassurance of the intended good.

Finally, the subjects' willingness to discuss their episodes of confusion suggests that the patient should be given the opportunity to talk about any experiences with confusion. As Schofield (1997) notes, this also gives the nurse an opportunity to explain what may have caused the delirium and to assure the individual that this was a temporary situation that is not uncommon. The nurse can initiate the discussion by saying, "Often older people experience a (confusion) episode while they are ill and may feel uncomfortable or uneasy afterwards. Are you having any of those feelings? Would you like to talk about them?"

## Conclusion

Subjects' recollections of a delirium episode reveal a frightening world of misinterpretations, hallucinations, paranoia, and loss of control. Things are not as they seem, and time passage is distorted. People are difficult to distinguish, and their motives are suspect. Patients' emotional responses to such episodes often include fear, anxiety, frustration, and anger. An enhanced awareness of the confused patient's reality may help the nurse to intervene more effectively with these clients. As one subject's daughter so aptly stated, "I know it had to be a horrible feeling for him to be confused and not know what was really going on. It was so real to him — it was really happening. Nobody knows until they walk in those shoes." ■

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