

HPNA PALLIATIVE NURSING MANUALS

Care of the Imminently Dying

EDITED BY

JUDITH A. PAICE

SERIES EDITED BY

BETTY R. FERRELL



OXFORD

HPNA PALLIATIVE NURSING MANUALS

Care of the Imminently Dying

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Series edited by: Betty R. Ferrell, RN, PhD, MA, FAAN, FPCN, CHPN

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Edited by

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Oxford University Press is a department of the University of Oxford. It furthers the University's objective of excellence in research, scholarship, and education by publishing worldwide.

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Published in the United States of America by

Oxford University Press

198 Madison Avenue, New York, NY 10016

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Library of Congress Cataloging-in-Publication Data

Care of the imminently dying / edited by Judith A. Paice.

p. ; cm. — (HPNA palliative nursing manuals; v. 7)

Includes bibliographical references.

ISBN 978-0-19-024428-6 (alk. paper)

I. Paice, Judith A., editor. II. Series: HPNA palliative nursing manuals ; v. 7.

[DNLM: 1. Hospice and Palliative Care Nursing—methods. 2. Chronic

Disease—nursing. 3. Palliative Care—methods. 4. Terminal Care—methods. WY 152.3]

RT87.T45

616.02'9—dc23

2015023115

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9 8 7 6 5 4 3 2 1

Printed in the United States of America

on acid-free paper

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Preface

This is the seventh volume of a new series being published by Oxford University Press in collaboration with the Hospice and Palliative Nurses Association. The intent of this series is to provide palliative care nurses with quick reference guides to each of the key domains of palliative care.

Content for this series was derived primarily from the *Oxford Textbook of Palliative Nursing* (4th edition, 2015), which is also edited by Betty Ferrell, Nessa Coyle, and Judith Paice, the editors of this series. The contributors identified in each volume are the authors of chapters in the *Oxford Textbook of Palliative Nursing* from which the content was selected for this volume. The *Textbook* contains more extensive content and references, so users of this Palliative Nursing Series are encouraged to use the *Textbook* as an additional resource.

We are grateful to all palliative care nurses who are contributing to the advancement of care for seriously ill patients and families. Remarkable progress has occurred over the past 30 years in this field, and nurses have been central to that progress. Our hope is that this series offers an additional tool to build the care delivery system we strive for.

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Chapter 1

Delirium

Debra E. Heidrich and Nancy K. English

Introduction

Delirium is a common neuropsychiatric disorder seen in all healthcare settings and is frequently underdiagnosed, misdiagnosed, and poorly managed. Often, patients are labeled as “confused,” and no further evaluation is performed to determine the cause of this confusion. This is particularly an issue with elderly patients, whose confusion is often dismissed as dementia, and for those with terminal illness, whose confusion may be accepted as part of disease progression. Patients at highest risk for delirium include those who are elderly, in intensive care units, or postoperative as well as those with advanced illnesses. This syndrome is associated with significant morbidity and mortality, leading to increased length of hospital and nursing home stays and risk for earlier death. The experience of delirium is frightening to both patients and their significant others; it impairs quality of living—and quality of dying. Prompt recognition and treatment are essential to improve patient outcomes, especially in the final stages of an illness.

Incidence, Prevalence, and Outcomes

Delirium is considered the most common and serious cognitive disorder in hospitals and in the palliative care setting.¹ Reported incidence and prevalence rates vary depending on the population being studied, criteria used to identify delirium, and setting. Delirium is reported to be found in 0.5% to 10% of community-based elders, 8.9% to 47% of institutionalized elders, 14% to 56% of hospitalized elders, 45% of elders after general anesthesia, 60% to 80% of mechanically ventilated adult patients in intensive care units, 26% to 62% of palliative care admissions, and 58.8% to 88% of persons in the weeks or hours preceding death.² However, the true incidence of delirium is unknown because it often goes undetected or misdiagnosed. Factors that contribute to a missed diagnosis include the following:

- History of a past psychiatric diagnosis or cognitive disorder, such as dementia, to which the symptoms may be attributed
- Acceptance of confusion as an expected consequence of old age and dying
- Presence of pain
- Transient and fluctuating nature of symptoms

- Imprecise and overlapping use of terminology, such as delirium, acute confusion, and terminal restlessness
- Inconsistencies in use of and types of assessment tools used to diagnose delirium

Delirium is associated with adverse physical, cognitive, and psychological outcomes. It is associated with short- and long-term decline in cognitive functioning and increases in falls, length of hospital stays, need for institutionalized care after hospitalization, and mortality. Although not everyone remembers their experience of delirium, those who do remember report having distressing feelings during the experience, including fear, anxiety, and feeling threatened.³

- Visual hallucinations of people or animals in the room intertwine with the people who are actually present to create a confusing and frightening experience.
- Procedures like injections may be interpreted as attempts to do harm, and interventions to reorient or reassure delirious patients may be met with suspicion and the fear that everyone is lying to them.
- Feeling threatened, the delirious patient may try to escape from the experience, leading to wandering behavior and falls as well as aggression toward caregivers.
- After the episode of delirium, persons report feeling humiliated and ashamed of their behavior while delirious. They also report a fear of experiencing delirium again in the future and may exhibit signs of post-traumatic stress disorder.
- Caregivers also experience distress related to delirium. Family members recall more symptoms of delirium than both the patient and the bedside nurse and are more distressed by the experience. Agitation and delusions or hallucinations are particularly distressing to both family members and nurses.
- Interventions to decrease the incidence of delirium and prompt treatment of delirium symptoms may help decrease caregiver distress.
- Providing information about delirium and support throughout this difficult time may reduce both acute and long-term distress in family members.³

Restlessness or agitation at the end of life, sometimes called “terminal restlessness” or “terminal delirium,” has been viewed as an expected part of the dying process.⁴ However, descriptions of terminal restlessness overlap considerably with the defining characteristics of delirium. Importantly, delirium is potentially reversible in some persons, even at the end of life. Given this potential for reversibility, a thorough evaluation of treatable causes of delirium is required, followed by appropriate interventions based on the patient’s overall condition and the goals of care.

A comprehensive plan for delirium that includes prevention, assessment and early detection, and appropriate intervention has the potential to save lives, improve quality of life, and significantly decrease costs.

Definition and Key Features of Delirium

Understanding the many symptoms, syndromes, and diagnoses associated with cognitive changes in persons with an advanced illness can be difficult at best. Terms such as confusion, acute confusion, delirium, and terminal restlessness are often used to describe changes in mental status without clear definitions or use of standard psychiatric classifications. The use of imprecise terminology can lead to mislabeling of behaviors, miscommunication among healthcare professionals, and misdiagnoses of cognitive changes. Therefore, the potential for the mismanagement of any cognitive change is extremely high.

The fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) criteria for delirium are listed in Box 1.1.⁵ Key features are that the disturbances develop over a short period of time, tend to fluctuate in severity during the course of a day, and represent a change from baseline. There are no diagnostic tests for delirium; the diagnosis is primarily clinical, based on careful observation and awareness of the criteria. Because the presentation of symptoms can sometimes be subtle, and symptoms fluctuate throughout the day, nurses, who have more frequent and continuous contact with patients, are crucial to the early recognition of delirium.

Disturbance in attention refers to a reduced ability to direct, focus, sustain, and shift attention. In delirium, the disturbed attention is combined with a *disturbance in awareness*, defined as having a reduced orientation to the environment. Patients may be hypoalert, slow to respond, or unable to maintain eye contact, or they may fall asleep between stimuli, requiring an increased amount of stimuli (touch, calling name) to elicit a response. Conversely, patients may be hyperalert, overreact to stimuli, startle easily, rapidly change from one topic to another in conversation, and exhibit signs of agitation. In the early stage of delirium, the abnormalities in attention and awareness may be subtle and easily overlooked.

Box 1.1 Diagnostic Criteria for Delirium

Disturbance in Attention and Awareness

The disturbance develops over a short period of time and tends to fluctuate in severity during the course of the day.

Disturbance in Cognition

The disturbances in criteria A and C are not explained by another preexisting, established, or evolving neurocognitive disorder; and do not occur in the context of a severely reduced level of arousal, such as coma.

History, physical examination, or laboratory findings indicate that the disturbance is caused by a medical condition, substance intoxication or withdrawal, or exposure to a toxin; or is because of multiple etiologies.

Source: Adapted from American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5). Arlington, VA: American Psychiatric Association; 2013.

Changes in cognition in delirium include memory deficit, disorientation, language disturbances, and perceptual disturbances. Disruptions in orientation usually manifest as disorientation to time or place, with time disorientation being the first to be affected. Short-term memory deficits are the most evident memory impairments. Patients may not remember conversations, television shows, or verbal instructions. Language disturbances include incoherent or jumbled speech, use of repetitive phrases, abnormally long pauses in the conversation, or difficulty finding the proper words to convey a message. Perceptual disturbances are no longer considered essential to the diagnosis of delirium.¹ When they are present, these disturbances may include misinterpretations, illusions, or hallucinations. Visual misperceptions and hallucinations are most common, but auditory, tactile, gustatory, and olfactory misperceptions or hallucinations can also occur.

Development over a short time and fluctuation during the course of the day are important considerations in both identifying delirium and differentiating it from dementia. In dementia, short-term memory problems occur progressively over months versus over hours or days with delirium. Importantly, persons with dementia are at high risk for developing delirium.² Obtaining a history of memory issues from the family is vital to establishing the patient's baseline because it is the change from the baseline that indicates delirium in persons with and without dementia.

Additional clinical features of delirium that are not included in the diagnostic criteria but are frequently present include sleep-wake cycle disruption, hallucinations or perceptual distortions, delusional or fixed false beliefs, and mood lability. Some of these features help in differentiating delirium from dementia because persons with dementia do not typically have delusions or hallucinations. "Sundowning," or increased confusion and agitation at night, should be viewed as a potential sign of delirium unless this behavior has been present for weeks to months in the person with dementia.

Subtypes of Delirium

There are three clinical subtypes of delirium based on arousal disturbance and psychomotor behavior: hyperactive, hypoactive, and mixed.

Hyperactive delirium is associated with hypervigilance, restlessness, and agitation.

Hypoactive delirium is characterized by confusion and somnolence.

The mixed subtype of delirium has alternating features of hyperactive and hypoactive delirium.

Subsyndromal delirium is described by some as occurring in persons who have some symptoms associated with delirium, but not enough symptoms to fit the criteria for the diagnosis of delirium. Persons who exhibit these more subtle symptoms are certainly at risk for developing the diagnosable syndrome of delirium. Clinicians need to intervene to eliminate as many factors that contribute to delirium as possible, and they need to monitor these patients routinely for progression to delirium.

Hyperactive delirium is identified more often in the clinical setting than the other subtypes because the symptoms of hypervigilance, restlessness, and agitation attract caregiver attention. However, the hypoactive and mixed forms appear to be more prevalent. The hypoactive form of delirium is likely underdiagnosed because symptoms are less noticeable, or it may be misdiagnosed as depression or fatigue.²

Delirium in the Final Days of Life and Death-Bed Phenomena

Most patients who exhibit signs of the dying process experience symptoms consistent with delirium.⁴ In a retrospective review, Chirco, Dunn, and Robinson found that delirium usually occurs 24 to 48 hours before death, with subtle signs being evident approximately 7 days before death.⁶ Delirium around the time of death is sometimes referred to as terminal restlessness, terminal delirium, terminal agitation, preterminal restlessness, preterminal delirium, or terminal psychosis. To avoid confusion, the qualifiers “terminal” and “preterminal” should be avoided, and standardized assessment tools should be used to diagnose delirium throughout the course of illness, including in the final phase of life.

Although delirium may be very frequent at the end of life, restless behaviors in the dying patient should not be accepted as simply “part of the dying process”; reversal of delirium maybe possible even in very advanced stages of illness.⁴ An evaluation to determine reversibility of a delirium is essential to facilitate a conscious, comfortable death whenever possible.

As death draws near, patients may experience apparitions of “helpers” or family members who have died and now appear to the patient as “guides” in the transition from life to death. These have been called death-bed visions (DBVs), and these often bring comfort to both patient and family. Patients have reported seeing angels, religious figures, spiritual guides, and deceased loved ones. It has been reported that 10% of patients are aware and conscious before death. Of these, approximately 50% to 60% are reported to have experienced a DBV.⁷

Hospice nurses, Callanan and Kelly, refer to these kinds of phenomena as “nearing death awareness” and define this concept as a special knowledge about the process of dying that may reveal what dying is like or what is needed to die peacefully.⁸ Themes of nearing death awareness include describing a place, talking to or being in the presence of someone who is not alive, knowing when death will occur, choosing the time of death, needing reconciliation, preparing for travel or change, being held back, and having symbolic dreams.

Death-bed phenomena may be differentiated from delirium-related hallucinations or misperceptions by observing verbal and nonverbal behaviors. Persons experiencing DBVs tend to be calm or questioning but not fearful of the visions, are able to focus their attention on the vision and describe the experience coherently to others, may converse with the persons in the vision, and are comforted and consoled by this experience.

Etiology

Delirium usually develops because of the interrelationship between patient vulnerability (predisposing factors) and noxious insults (precipitating factors).⁹ Table 1.1 identifies some of the common predisposing and precipitating factors for delirium. Although a single precipitating factor in the predisposed

Table 1.1 Predisposing and Precipitating Factors for Delirium

Predisposing Factors	Precipitating Factors
<i>Demographic characteristics</i>	<i>Drugs</i>
Age of 65 years or older	Sedative hypnotics
Male sex	Narcotics
<i>Cognitive status</i>	Anticholinergic drugs
Dementia	Treatment with multiple drugs
Cognitive impairment	Alcohol or drug withdrawal
History of delirium	<i>Primary neurologic diseases</i>
Depression	Stroke, particularly nondominant hemispheric
<i>Functional status</i>	Intracranial bleeding
Functional dependence	Meningitis or encephalitis
Immobility	<i>Intercurrent illnesses</i>
Low level of activity	Infections
History of falls	Iatrogenic complications
<i>Sensory impairment</i>	Severe acute illness
Visual impairment	Hypoxia
Hearing impairment	Shock
<i>Decreased oral intake</i>	Fever or hypothermia
Dehydration	Anemia
Malnutrition	Dehydration
<i>Drugs</i>	Poor nutritional status
Treatment with multiple psychoactive drugs	Low serum albumin level
Treatment with many drugs	Metabolic derangements (e.g., electrolyte, glucose, acid–base)
Alcohol abuse	<i>Surgery</i>
<i>Coexisting medical conditions</i>	Orthopedic surgery
Severe illness	Cardiac surgery
Multiple coexisting conditions	Prolonged cardiopulmonary bypass
Chronic renal or hepatic disease	Noncardiac surgery
History of stroke	<i>Environmental</i>
Neurologic disease	Admission to an intensive care unit
Metabolic derangements	Use of physical restraints
Fracture or trauma	Use of bladder catheter
Terminal illness	Use of multiple procedures
Infection with human immunodeficiency virus	Pain
	Emotional stress
	<i>Prolonged sleep deprivation</i>

Source: Adapted from Inouye S. Delirium in older persons. *N Engl J Med.* 2006;354:1157–1165.

patient may be enough to lead to delirium (e.g., a single dose of an anticholinergic medication in a patient with dementia), there are often multiple factors involved in the development of delirium. Addressing only a single factor likely will not aid in improving delirium; an approach that addresses as many predisposing and precipitating factors as possible is needed for resolution.

Nurses must be aware of the increased risk for delirium in patients with dementia, carefully assess for signs of delirium, and work to eliminate or decrease precipitating factors that can be controlled. Too often, changes in behavior are dismissed as signs of the individual's dementia instead of being identified as signs of delirium. Table 1.2 identifies the factors that help in differentiating dementia from delirium.¹⁰ Knowledge of the patient's baseline cognitive status is critical for identifying recent changes in cognition and attention.

Several studies have identified key factors that increase the risk for delirium in subsets of populations.

Despite an incidence rate of 40% to 80% in persons with cancer, delirium is rarely appreciated as a source of symptom distress in oncology settings.¹¹ Table 1.3 outlines the cancer-specific considerations as they relate to the risk factors for delirium, illustrating that persons with cancer have many predisposing risk factors and are exposed to multiple precipitating factors for delirium.

Studies of patients undergoing surgery showed that preoperative cognitive deficits, preexisting depression, and impaired vision are common predisposing factors for delirium; in addition, duration of surgery, prolonged intubation, surgery type, and elevated inflammatory markers are frequent precipitating factors for postoperative delirium.

In the hospice and palliative care setting, poor sleep quality, uncontrolled pain, multiple medications (including high dose opioids), dehydration, infection, dementia, and organ failure are associated with delirium.

Five risk factors for persistent delirium in elderly patients at discharge from the hospital include dementia, vision impairment, functional impairment, high comorbidity, and use of physical restraints during delirium.⁹

Assessment

Comprehensive and ongoing assessment is necessary to identify patients at risk for delirium and to enable early detection of delirium. Standardized assessment tools for delirium administered by healthcare providers trained in using these tools improves the identification of delirium in the clinical setting.¹ Assessment tools include those designed to screen for delirium symptoms, those designed to make a formal diagnosis of delirium, and those designed to rate the severity of delirium.

The Mini-Mental State Examination (MMSE) is a 20-item screening tool that provides a clinical evaluation of cognitive function but is not specifically designed to assess for delirium and does not differentiate between dementia and delirium.¹² It assesses orientation, attention, recall, and language function. The MMSE is widely used in practice and research, and data support the scoring system to identify the severity of cognitive impairment. The length of this

Table 1.2 Differentiating Delirium From Dementia

	Delirium	Dementia
Onset	Acute or subacute, occurs over a short period of time (hours to days).	Insidious, often slow and progressive.
Course	Fluctuates over the course of the day, worsens at night. Resolves over days to weeks.	Stable over the course of the day; is progressive.
Duration	If reversible, short term.	Chronic and nonreversible.
Consciousness	Impaired and can fluctuate rapidly. Clouded, with a reduced awareness of the environment.	Clear and alert until the later stages. May become delirious, which will interfere.
Cognitive defects	Impaired short-term memory, poor attention span.	Poor short-term memory; attention span less affected until later stage.
Attention	Reduced ability to focus, sustain, or shift attention.	Relatively unaffected in the earlier stages.
Orientation	Disoriented to time and place.	Intact until months or years with the later stages. May have anomia (difficulty recognizing common objects) or agnosia (difficulty recognizing familiar people).
Delusions	Common, fleeting, usually transient and poorly organized.	Often absent.
Hallucinations	Common and usually visual, tactile, and olfactory.	Often absent.
Speech	Often uncharacteristic, loud, rapid, or slow (hypoactive).	Difficulty in finding words and articulating thoughts; aphasia.
Affect	Mood lability.	Mood lability.
Sleep-wake cycle	Disturbed; may be reversed.	Can be fragmented.
Psychomotor activity	Increased, reduced, or unpredictable; variable depending on hyperdelirium or hypodelirium.	Can be normal; may exhibit apraxia.
Source: Adapted from Milisen K, Braes T, Fick D, et al. Cognitive assessment and differentiating the 3 Ds (dementia, depression, delirium). <i>Nurs Clin North Am.</i> 2006;41:1–22.		

examination and the writing and drawing questions included in it may be cumbersome and difficult to perform in a palliative care population. A subset of four items from the MMSE may be adequate to screen for delirium and cognitive impairment: current year, date, backward spelling, and copy a design.¹²

Table 1.4 provides an overview of the instruments used to assess delirium. These instruments are reviewed because they distinguish delirium from dementia and assess at least several of the multiple features of delirium. Although all of these instruments require further study to determine application across varied settings and among different patient populations, the

Type of Physiologic Risk Factor	Cancer-Specific Considerations
Nutritional deficiencies B vitamins Vitamin C Hypoproteinemia	<ul style="list-style-type: none"> ● Symptom distress: nausea, emesis, mucositis, diarrhea, pain, and anorexia or cachexia syndrome ● Surgical alteration of the head and neck region or gastrointestinal tract ● Nonoral feeding routes: gastrostomy feeding tube and use of total parenteral nutrition
Cardiovascular abnormalities Decreased cardiac output states: myocardial infarction, dysrhythmias, congestive heart failure, and cardiogenic shock Alterations in peripheral vascular resistance: increased and decreased states Vascular occlusion: emboli and disseminated intravascular coagulopathy	<ul style="list-style-type: none"> ● Septic shock syndrome ● Hypercoagulopathy and hyperviscosity ● Anthracycline-related cardiomyopathy ● Central line occlusion ● Thrombi associated with immobility and paraneoplastic syndromes ● Disseminated intravascular coagulopathy
Cerebral disease Vascular insufficiency: transient ischemic attacks, cerebral vascular accidents, and thrombosis Central nervous system infection: acute or chronic meningitis, brain abscess, and neurosyphilis Trauma: subdural hematoma, contusion, concussion, and intracranial hemorrhage	<ul style="list-style-type: none"> ● Intracerebral bleed caused by thrombocytopenia ● Meningeal carcinomatosis ● Central nervous system edema secondary to brain malignancy or whole brain radiation therapy ● Fall risk ● Malignancy: primary or metastatic involving brain and cranial irradiation
Endocrine disturbance Hypothyroidism Diabetes mellitus Hypercalcemia Hyponatremia Hypopituitarism	<ul style="list-style-type: none"> ● Mantle field radiation therapy ● Steroid induced ● Related to bone metastases ● Syndrome of inappropriate antidiuretic hormone, rigorous hydration, and dehydration ● Brain tumor in or adjacent to pituitary gland
Temperature regulation fluctuation Hypothermia Hyperthermia	<ul style="list-style-type: none"> ● Absence of customary warm clothes ● Fever
Pulmonary abnormalities Inadequate gas-exchange states: pulmonary disease and alveolar hypoventilation Infection: pneumonia	<ul style="list-style-type: none"> ● Hypoxemia ● Anemia ● Lung metastases ● Bleomycin-induced pulmonary fibrosis ● Radiotherapy to chest ● Chest tubes ● Neutropenia and immobility

(continued)