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BEHAVIORS ASSOCIATED WITH DEMENTIA

Whether resisting care or exhibiting apathy, an older adult with dementia is attempting communication. Nurses and other caregivers must learn to ‘hear’ this language.

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OVERVIEW: Seemingly simple adjustments in care routines and approaches can make a significant difference in the experiences of people with dementia. This article provides an overview of cognitive impairment in older adults and suggests interventions that can help providers understand the “behavioral symptoms” of dementia, which are often considered a way of communicating unmet needs. By focusing on the person rather than on the disease, nurses promote comfort and functional autonomy in older adults whose cognitive impairments have progressed and yet who are very much alive and deserving of respectful, dignified care.

“No! No! No!” cries Esther Lattimore.
“But we need to get you washed up,” the nursing assistant explains.
“No! No! Not that, no! Stop. Stop!” Ms. Lattimore cries, grabbing the aide’s arm.
“That hurts! You stop it!” counters the aide, angry now as she tries to loosen the grip on her forearm. “Here I am, trying to help you, and you’re just being mean! Now, let go!”
Most nurses, regardless of setting, will recognize the challenges of treating people like Ms. Lattimore, whose behaviors may be puzzling or out of character or do not fit the situation at hand. These behaviors often signal distress and cause additional problems for both the person

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A NEW LOOK AT THE Old



Messiah Village, a retirement community in Mechanicsburg, Pennsylvania, offers extended care for people with dementia and also features a day care center for children. One of the first “intergenerational” programs in the country, the center encourages interactions among its oldest and youngest clients. Photograph taken from *Aging in America: The Years Ahead*, by photographer Ed Kashi and writer Julie Winokur.

APATHY

Behavior: Roslyn Jensen sits in her room, staring out the window. Her nurse says, "It's a beautiful day out there, isn't it? Aren't the flowers pretty?" Ms. Jensen looks blankly at her and doesn't reply. Touching Ms. Jensen's arm, the nurse tries again. "You used to have a big flower garden, right?" Quietly, she replies, "Yes, I did."

Intervention: Although flowers were once a focus of Ms. Jensen's life, she now seems indifferent to them. The nurse persists, "Come with me to the activity group. You can help us name all those flowers in the courtyard." She takes Ms. Jensen's hand and gently tugs to get her to stand up. "We really need your help," she says. "We'll have fun, I promise!" Shaking her head, Ms. Jensen gets up from her chair, follows the nurse, and once there, participates.

and others in the environment, including caregivers. In many situations, the behaviors observed are the result of cognitive impairment, a global term that describes a wide range of disabilities that vary from mild to severe.

Nurses can expect to encounter an increasing number of older adults with cognitive impairment and the accompanying behavioral symptoms. A classic study found that among older adults living in the community, one in 10 over age 65 and nearly half of those over age 85 have dementia.¹ Rates among institutionalized older people are even higher, as nearly half of nursing home residents have dementia, and recent evidence suggests rates in assisted living facilities exceed 60%.^{2,3} An estimated 4.5 million Americans currently have Alzheimer disease, a number that is predicted to grow to over 13 million by 2050.⁴ Of equal importance, 83% of older adults with a cognitive disorder also experience behavioral symptoms.⁵ As has been noted elsewhere, behavioral and psychological symptoms of dementia "are a major source of distress for caregivers and often lead to institutionalization"⁶; therefore, family caregivers' needs are often an important focus of nursing care, including education on managing behavioral symptoms.

This article describes cognitive impairment; ways of assessing behavioral symptoms in a person with dementia; and nonpharmacologic interventions that take into consideration the person's environment, personality, and potential unmet needs.

LATE-LIFE COGNITIVE IMPAIRMENT

Cognition refers to the ability to execute complex mental processes such as learning, perceiving, making decisions, and remembering. Many older adults are concerned about memory changes and may panic when they misplace car keys, fearing the onset

of dementia. Normal, age-associated memory loss is characterized by brief lapses, such as forgetting a name or phone number.

Cognitive impairment exists on a continuum, from what's known as "mild cognitive impairment" to dementia; differentiation is made by the number, type, and severity of the deficits in mental capacity a person exhibits. These may include memory loss (impaired ability to learn new information or to recall previously learned information), aphasia (loss of ability to use language to communicate), agnosia (loss of the ability to comprehend the meaning of sensory stimuli, as in the inability to recognize objects or people), apraxia (loss of ability to make voluntary movements), and disturbances in the executive functions (planning, organizing, sequencing, abstracting).

Mild cognitive impairment results in significant and persistent memory deficits, yet people with it remain functional and independent in most ways, without other clinical signs of dementia. However, in as many as 12% to 15% of people with mild cognitive impairment, the cognitive deficit progresses to Alzheimer disease, the primary cause of dementia, each year.⁷ This is important because early treatment of Alzheimer disease may delay debilitating brain changes and further cognitive decline, allowing time for counseling and health care planning.

Dementia refers to a global loss of cognitive and intellectual functioning, caused by damage to the brain, that is severe enough to interfere with social and occupational performance.⁸ Dementia is a general clinical term that refers to a group of disorders that have common symptoms but different causes. The etiology of dementia varies and may be due, for example, to Parkinson disease, Huntington disease, or AIDS, or it may result from one or more of the neurodegenerative disorders described briefly below.

COMMON TYPES OF DEMENTIA

Although impaired memory and cognitive disturbance are characteristics of all dementias, the specific cognitive, emotional, and behavioral deficits the person with dementia experiences will differ depending on the type of dementia, stage of disease, comorbid conditions, and individual factors. Moreover, one or more causes of dementia can coexist, as in the case of the older adult suffering from both Alzheimer disease and vascular dementia, and cause a "mixed" symptomatology, in which the characteristic losses of more than one disease are seen. As a result, knowing the type of dementia is important to guiding decisions about nursing interventions. Prevalence rates of Alzheimer disease and other dementias vary from study to study, depending on the source of subjects, methods used to assess

THE LANGUAGE OF DEMENTIA CARE

Changes in labeling are effecting changes in care.

The last two decades have seen a dramatic shift in the way people with dementia, and the behaviors they exhibit, are regarded, labeled, and “treated.” Early dementia care emphasized loss and disability, labeled behaviors such as wandering or vocalizations with negative terms such as “disruptive” and “disturbing,” medicalized people with dementia by calling them patients, and offered largely impersonal, custodial care for their “hopeless” and “inevitable” decline.

The importance of individualized approaches that emphasize the person, not the diagnosis, was underscored by Tom Kitwood in *The New Culture of Dementia Care*.¹ In this 1995 text, Kitwood and the Bradford Dementia Group seriously challenged the “old culture” and advocated new language and practices that viewed the person with dementia as a person foremost—one whose “abilities, tastes, interests, values, and spirituality” were more important than the disabilities created by dementia. The movement toward more positive views of dementia care

has been under way since the mid-1980s. The goal is care that emphasizes remaining abilities and strengths, promotes engagement in meaningful activities, and stresses capability.

This shift is being reflected increasingly in the language used to describe people with dementia and the behaviors they display; interventions also have begun to place a greater emphasis on understanding and accommodation than on control. Models of nursing care reflect this shift as well and call for all nurses to reconsider their attitudes toward dementia care and change the powerful descriptive labels they use.

Just as simple changes in care practices have considerable effects on nursing care outcomes, changes in labels applied to older adults with dementia can clearly influence attitudes and actions that shape the quality of their lives.

REFERENCE

1. Kitwood T, Benson S, editors. *The New Culture of Dementia Care*. London: Hawker Publications Ltd; 1995.

cognitive impairment, and definitions of dementia. However, all reports agree that the number of people living with dementia will increase dramatically as the population ages.

Alzheimer disease is the most common type of dementia. Characterized by the presence of neurofibrillary plaques and tangles in the brain, it can be caused by a variety of genetic, environmental, and other factors. The prevalence of Alzheimer disease increases markedly with advancing age, with the highest rates among those 80 years and older. Diagnostic criteria include the presence of cognitive deficits, including memory impairment and one or more additional cognitive disturbances (aphasia, agnosia, apraxia, or changes in executive functioning), significant decline from previous levels of functioning, and gradual and continuous decline of ability. Behavioral symptoms are not common in early stages; even memory loss is often concealed by use of preserved social skills and memory aides. Over an eight-to-10-year period, increasing functional dependence and loss of ability to manage aspects of daily life (such as shopping, food preparation, medication and financial oversight, and driving) is observed. Eventually, grooming, toileting, bathing, dressing, and eating become impaired.

Dementia with Lewy bodies is characterized by the presence of concentric hyaline intracytoplasmic inclusions (called Lewy bodies) that also define Parkinson disease. Progressive cognitive decline occurs early, but significant memory impairment may not become evident until later stages of the disease. Other core clinical features that distinguish dementia with Lewy bodies from Alzheimer disease include fluctuating cognition (with variation in attention and alertness), recurrent visual hallucinations, and motor deficits consistent with parkinsonism. Associated features include sleep disturbance, syncope and falls (necessitating vigilant fall-risk assessment and management), and sensitivity to antipsychotic agents that are commonly used to treat hallucinations and delusions.

Vascular dementia is caused by decreased blood flow to the brain (secondary to hypertension, carotid artery disease, hyperlipidemia, or smoking), with significant enough damage to cause cognitive impairment. As in Alzheimer-type dementia, memory impairment and other cognitive changes are observed. Additional diagnostic criteria include the presence of focal neurologic signs or evidence of cerebrovascular disease and strokes, as revealed on neuroimaging. Gait difficulties, falls, sudden per-

SUDDEN WITHDRAWAL

Behavior: Edward Bateman pushes his chair away from the dinner table and rises to leave after taking only a few bites of food. "Aren't you hungry today, Mr. Bateman?" asks the nurse as she walks toward him. He puts his hand up as if to keep her away, frowns, glances around, and promptly walks out of the room. This is not the first time Mr. Bateman has withdrawn from the active and sometimes noisy dining area. Staff accept that Mr. Bateman "knows" when the stimulation is too much and accommodate his wish to leave.

Intervention: A simple plate of food and a glass of milk are delivered to Mr. Bateman's room. The nurse coaxes him, "Try this nice sandwich. It's grilled cheese, your favorite." When he takes a bite, she continues to cue him: "Now how about a drink of cold milk?" In the quiet of his room, Mr. Bateman eats most of his lunch.

sonality and mood changes, and stepwise deterioration are also characteristic.

Frontotemporal dementia is characterized by changes in the frontal and temporal lobes of brain, which control reasoning, personality, social behavior, and speech. The intracytoplasmic argentophilic neuronal inclusions (Pick bodies) that gave the condition its original name, Pick disease, are not necessarily present on autopsy, a finding that has led to greater use of the term *frontotemporal dementia*. Unlike other dementias, changes in personality, behavioral disinhibition, and language problems are often the first symptoms. Mood and behavioral changes, which often precede memory impairment, include apathy, a lack of concern about oneself or others, a loss of initiative, social withdrawal, compulsive or repetitive behaviors, inappropriate sexual behaviors, impaired judgment or decision making, and dangerous behaviors caused by lack of inhibition and insight. Compared with Alzheimer disease, onset after age 75 years is rare, memory impairment in early stages is less apparent, and motor abnormalities are more prominent. The profound disinhibition associated with frontotemporal dementia requires individualized nursing interventions to provide a safe and structured environment.

Creutzfeldt-Jakob disease is a rare, progressive neurologic disorder that occurs in people of all ages, but typically occurs between ages 40 and 60 years. A subacute spongiform encephalopathy caused by transmissible agents known as "slow viruses," or prions, it's believed by some to be linked to bovine spongiform encephalopathy (commonly known as "mad cow disease"). Clinical manifestations often occur in a triad that includes dementia plus involuntary movements (particularly myoclonus) and peri-

odic activity seen on electroencephalography. Once symptoms appear, decline is rapid and death usually occurs within one year. Normal sterilization procedures do not kill the prions that cause this disease, requiring use of special procedures (developed in consultation with the infection control department of each facility) to protect health care workers and other patients alike.

Delirium, depression, and adverse effects of medication may also trigger dementia-like syndromes, which can overlap with existing dementia or appear independently. Behavioral symptoms caused by these and other health conditions may be reversed or arrested. Comprehensive assessment for all possible causes of symptoms of cognitive impairment is essential. For example, a person with dementia may experience depression that causes loss of interest, dysphoria, impaired concentration, and fatigue that deepens apathy, withdrawal, and memory impairment. By treating the depression, the additional disability is removed, allowing the person to function as well as he can.

BEHAVIORAL SYMPTOMS OF DEMENTIA

A wide variety of symptoms throughout the course of dementia have been observed, including those that may be directly linked to cognitive deficits. For example, memory loss may result in losing or misplacing items and precipitate suspicions that someone is stealing things. Aphasia may cause a person to omit words ("Oh, it was so . . . you know, at the . . . with all the people . . . at the, you know"), and

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may result in neologisms (made-up words; “pintin” for peanut, for example), or substituting descriptions for names of things (“tick-tock” for clock). Agnosia may contribute to odd behavior, such as putting dentures in the refrigerator or attempting to brush hair with a toothbrush. Behavior may also be specific to the type of disease, such as the anger, apathy, disinhibition, poor hygiene, and poor judgment characteristic of frontotemporal dementia.

Because of perceptual, language, and memory deficits, people with dementia often have difficulty in understanding and talking about the sources of their discomfort. As a result, they often express themselves through actions. For example, Ms. Lattimore was not able to articulate why she did not want to bathe, but she was clearly telling the caregiver that that was the case, through speech (“No, no, no!”) and behavior (grabbing the caregiver by the arm).

Among the most common noncognitive behavioral symptoms are apathy and withdrawal; anxiety; irritability; dysphoria and depression; disinhibition; delusions, hallucinations and paranoia; agitation and aggression; activities such as wandering, purposeless behavior, or socially improper behaviors; disturbed diurnal or circadian rhythms that cause sleep changes; loss of the ability to feed oneself; and resistance to care.^{9,10} These symptoms aren’t present in all people with dementia, they don’t necessarily progress with the other aspects of the disease, and they are often considered “secondary symptoms” that respond to both drug therapy and supportive intervention.⁹

Behavioral symptoms of dementia may result from more than one cause. For example, agitation can be caused by the need to urinate, as well as by depression. Anxiety and sudden withdrawal at mealtimes may result from a noisy, crowded, or chaotic environment, the person’s inability to identify utensils or the food itself (because of agnosia), or dysphagia and the fear of choking. Hitting, biting, and screaming at bath time may be the result of pain, uncomfortable room or water temperature, embarrassment or a lack of privacy, or the fear of sexual assault.¹¹ In most cases, the type and extent of symptoms result from complex interactions among the type of dementia, longstanding personality traits and patterns of behavior, and biologic and environmental factors.^{12,13} Considerable observation is often required to understand the “problem” from the perspective of the person with dementia.

ASSESSMENT

While broad terms like *agitation* are used to describe a wide range of behaviors—from irritability and restlessness to wandering and lashing out—

TABLE 1. ASSESSMENT TOOLS

NEUROPSYCHIATRIC INVENTORY¹
<ul style="list-style-type: none"> • Assesses for 12 neuropsychiatric disturbances commonly seen in dementia: delusions, hallucinations, agitation, dysphoria, anxiety, apathy, irritability, euphoria, disinhibition, aberrant motor behavior, night-time behavior disturbance, and appetite and eating abnormalities • Includes caregiver report • Rates the severity and frequency and assesses the level of caregiver distress
BEHAVIORAL PATHOLOGY IN ALZHEIMER DISEASE RATING SCALE²
<ul style="list-style-type: none"> • 25 questions evaluate 7 areas of possible disturbance: paranoia and delusion, hallucination, activity disturbance, aggressiveness, diurnal rhythm disturbance, affective disturbance, and anxiety and phobia • Includes caregiver report • Rates questions on a 4-point scale, from “not present” to “present and intolerable to caregivers”
COHEN-MANSFIELD AGITATION INVENTORY³
<ul style="list-style-type: none"> • Assesses for 36 behaviors that represent verbal and physical agitation • Includes caregiver report • Rates items on 7-point scale, from “never” to “several times an hour”
AGITATED BEHAVIOR IN DEMENTIA SCALE⁴
<ul style="list-style-type: none"> • Assesses for 16 behaviors that represent verbal and physical agitation • Includes caregiver report • Rates items for frequency using a 4-point scale, from “did not occur in this week” to “occurred daily or more often,” and caregiver reaction on a 5-point scale, from “not at all” to “extremely”
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<ol style="list-style-type: none"> 1. Cummings JL. The Neuropsychiatric Inventory: assessing psychopathology in dementia patients. <i>Neurology</i> 1997;48(5 Suppl 6):S10-6. 2. Reisberg B, et al. Behavioral symptoms in Alzheimer’s disease: phenomenology and treatment. <i>J Clin Psychiatry</i> 1987;48 Suppl:9-15. 3. Cohen-Mansfield J. Measurement of inappropriate behavior associated with dementia. <i>J Gerontol Nurs</i> 1999;25(2):42-51. 4. Logsdon RG, et al. Assessment of agitation in Alzheimer’s disease: the Agitated Behavior in Dementia Scale. Alzheimer’s Disease Cooperative Study. <i>J Am Geriatr Soc</i> 1999;47(11):1354-8.

RESISTIVENESS

Behavior: “No, no, no! Get away from me. I’m not like that. Leave me alone!” screams Joseph Greenberg as the nurse’s aide tries to remove his pajama top. “But you can’t run around in PJs all day, Mr. Greenberg. Let’s get you dressed,” the aide replies. “Don’t you touch me, you slut!” he yells, pushing her hand away.

Intervention: His reference to “not being like that” and name-calling suggest that the caregiver’s sex might play a role. A male nurse is sought and he is able to help Mr. Greenberg remain calm while he is dressed and groomed.

the development of effective interventions relies on understanding the nature of the behavior and the message it expresses. It’s important to know the person’s traits and habits and to work with interdisciplinary teams on all shifts to identify and solve problems. In many situations, documentation of behaviors is needed to better understand what leads to them; it may help clinicians to understand whether the changes are related to a progressive loss of function or stress resulting from environmental triggers. Personalized “behavior logs” can ensure that behaviors are systematically recorded. Like standardized scales, these logs may be used to document increases or decreases in behavior.

Both descriptive assessment (noting where, when, and with whom behaviors occur) and standardized assessment procedures are valuable when developing nursing interventions. Various scales are available; each assesses a somewhat different set of behaviors and employs slightly different methods of collecting information. (See Table 1, page 45.) Nonetheless, all serve the important function of helping caregivers differentiate behaviors so that specifically tailored interventions can be developed.

NURSING CARE MODELS

The complex interaction among personal, social, and physical factors and behavioral and psychological symptoms can be assessed using two nursing care models. Both models are based on the belief that psychological and behavioral symptoms in dementia are a form of communication.

The Progressively Lowered Stress Threshold Model was developed in response to the observed behaviors of older adults with Alzheimer disease and related disorders.¹⁴ According to this model, adults with dementia become less able to manage stress as the disease progresses. That is, their “stress threshold” is lower, resulting in anxiety and increasingly dysfunctional behaviors as stress builds. Stressors may include fatigue; changes in routine,

caregiver, or environment; demands that exceed the person’s ability to function; multiple and competing stimuli; perceptions of loss; and physiologic factors such as illness, pain, discomfort, and adverse effects of medications.¹⁵

Six essential principles of care are proposed, including strategies to modify the environment to ensure safety; provide “unconditional positive regard”; use anxiety and avoidance as gauges of activity and stimulation levels; teach caregivers to “listen” to behaviors; modify environments to support losses and enhance safety; and provide ongoing education, support, care, and problem solving to caregivers. Promoting comfort and function, by understanding and managing personal, social, and physical factors that may trigger behaviors, is paramount.

The Need-Driven Dementia-Compromised Behavior Model, developed in 1993, “changes the prevalent view of dementia-related behaviors as ‘disrup-

MY STEPFATHER IN THE NURSING HOME

For lunch he wears a clean white shirt, strapped into his wheelchair with his hair smoothed back, the shoulders of his good Brooks Brothers jacket straight. He takes a tiny sip of water, puts down his glass, forgets and picks it up, twelve times. Strangers he once knew pass through the lobby of his mind, ask him questions he can’t answer, change his sheets and towels. He throws his tray across the room and howls the hotel’s lost his luggage just when he’s close to a big deal. He can’t find a pencil, does the math in his head, and everyone’s stealing his money. He tries to tell the nurse he’ll get her a job in sporting goods (the company he built from scratch, nights, weekends), but the sentences slur like acrobats who’ve lost their timing. I remember he’d choke up reading every heartbreak story in the Denver Post. Afterwards he’d send a check.

—Wendy Drexler, senior editor at Educators Publishing Service, Cambridge, MA

tive' or 'disturbing' to a perspective that conceptualizes these behaviors as potentially understandable needs that, if responded to appropriately, enhance quality of life."¹⁶

In this model, behavioral symptoms are considered to be the result of complex interactions between "background" and "proximal" factors. Background factors are relatively stable individual and disease-related characteristics that may predispose a person with dementia to behavioral symptoms. There are four groups of background factors: dementia-compromised functioning (such as language impairment), poor overall health status, demographic variables (such as marital status), and psychosocial variables (such as personality traits). Proximal factors are "those that induce a need state" that precipitates behavioral symptoms. The four groups of proximal factors are unmet physiologic need (such as hunger), unmet psychosocial need (such as contact with friends), disturbing environmental factors (such as a cold room), and uncomfortable social surroundings (such as too many people in a room). Proximal factors are used as a basis for developing nursing interventions.

PRINCIPLES OF CARE

A number of reasonably simple nursing interventions may reduce the risk of inadvertently precipitating behavioral symptoms. Many involve minor changes in the way care is provided. The overall goal of care—to enhance self-respect by promoting comfort and dignity—is often best achieved by focusing on the person's abilities and successes instead of disabilities and failures. Caregivers can ensure that the person is able to use his remaining abilities by minimizing the adverse effects of other health conditions, sensory impairment, and cognitive deficits while optimizing social and environmental factors that support functional capacity.

Adjust daily routines to focus on the person, not the tasks. Attempts to force a person with dementia into routines that are convenient for staff or family caregivers but are inconsistent with the person's lifelong history or needs too often result in resistance and intensified behavioral and psychological symptoms. For example, a morning shower may be confusing or frightening to someone who always took evening baths. Similarly, someone who has always been a night owl may require care planning to accommodate nighttime wakefulness, not a medical intervention for insomnia. Likewise, eating is another highly personal, but often neglected, area. Offering food that is familiar and enjoyed, that can be eaten safely and with dignity, and that is offered at times other than regular meals is often important to maintaining hydration and nutrition. Finally, clothing that's easy to wear and wash (for example,

TIPS FOR NURSES BY HEALTH CARE SETTING

Hospital

Acute confusion (delirium) is common among hospitalized older adults, and may overlap with existing dementia. Prompt mental-status and confusion assessments, combined with a baseline behavior history, permits identification of both conditions, development of interventions, and discharge planning.

Nursing home

High-quality dementia care in long-term care settings is facilitated by nurses acting as role models (by demonstrating how care can be provided), advocates (by encouraging team members to think about behavior as communication), and teachers who provide both formal and informal instruction to nursing assistants and other caregivers.

Ambulatory care

Nurses' assessment of older adults' cognitive symptoms and family complaints about changes in behavior increase the chance that impairment will be identified early. In turn, cholinesterase inhibitors, health counseling and family education, and referral to resources that promote living in the community may be provided.

Home care

Dementia-related symptoms often precipitate placement in long-term care. Viewing those with dementia and their family caregivers as equal participants in care planning increases the likelihood that education, respite care, and referral to services such as adult day care are provided.

pants with elastic waists, sweaters with zippers instead of buttons, and shoes with Velcro closings) can promote independence.

Adjust interaction and communication strategies. Three steps toward communication are getting the person's attention, making eye contact, and speaking directly to the person (unless this is culturally inappropriate) to ensure he perceives the message.¹⁷ Nonverbal communication is of equal importance, including tone of voice, facial expressions, and use of nonverbal gestures (for example, showing the person how to brush her teeth while saying "brush your teeth").¹⁸ Slowing down the pace of speech, using short sentences, and using nouns (chair, bathroom) instead of pronouns (it, there) will help. Avoiding commands that include the word "don't" and questions that begin with "why" may prevent a feeling of being reprimanded or tested.

Respect is conveyed by not reminding the person of his disabilities. Well-meaning but misguided care-

AGITATION

Behavior: Agatha Rittmeister walks down the hall, calling out “Where am I? Where am I? Is it all right?” As her cries become louder, her frightened facial expression signals that she is becoming more agitated.

Intervention: Establishing eye contact, the nurse says in a soothing voice, “Ms. Rittmeister, I’m so glad to see you. I need your help. Can you come with me, please?” She extends her hand and smiles. Ms. Rittmeister continues to look confused, but pauses. The nurse continues, “Come to the kitchen. I have some cookies for you to taste.” Still looking a bit puzzled, Ms. Rittmeister replies, “Well, all right. I suppose,” and begins to walk toward the kitchen with the nurse.

givers can worsen anxiety and frustration by asking the person to “try harder.” (For example, “You did it yesterday; what’s the problem today?” Or “If you wanted to, you could do it.”) Breaking down tasks into steps, while providing encouragement and reassurance, helps the person to act as independently as possible. Likewise, confronting delusions with facts is rarely reassuring. For example, instead of responding to someone who says she is going to see her father with “Your father is dead,” it’s better to distract her by reminiscing with her about her childhood.

Although it’s common to rephrase a question a person doesn’t understand, this could actually increase confusion. Instead, ask only one question at a time, allow time for a response, and repeat the question if needed. Another common error is to assume that there’s no point in explaining procedures or care because the person won’t understand. On the contrary, providing guidance will minimize surprises. For example, when approaching a person with dementia, a nurse should first identify herself and address him by name, then explain in simple terms what she will do. A silent approach from behind may be unnecessarily frightening. And people with sensory impairments must have eyeglasses, hearing aids, and adequate lighting; without them, misinterpretations of stimuli can lead to behavioral or psychological symptoms.¹⁹

Change reactions and responses to behavior. A tendency to repeat questions is common in people with dementia. The untrained caregiver may find this repetition monotonous and annoying, think that the behavior is purposeful, and become angry or withdraw in response. Instead, when a person repeats a question, the educated caregiver will listen carefully to detect the real message. For example, someone repeatedly asking “When is lunch?” may be hungry or thirsty and should be offered food or drink.

In a similar vein, people with dementia may say or do things that caregivers don’t understand or that they find silly. For example, a woman may try to “go to work” after 20 years of retirement or ask to see parents who have been dead for decades. It’s easy to view these as meaningless delusions, yet they may be better understood as attempts to remain engaged in life. Having a “workplace,” or engaging in an activity such as gardening, food preparation, or reminiscence, may provide a therapeutic distraction. By providing assistance early, rather than ignoring behaviors or hoping they will stop on their own, nurses may avoid more intense and disconcerting behaviors.

Monitor and adjust the environment. No matter what the environment, people with dementia need structure and routine and a focus on preserving their capabilities by adjusting surroundings. Simple adjustments, such as placing a clock and calendar in the room, may help those still oriented to time and place. Family photographs, a favorite pillow, or familiar bed clothing can reassure, as well. Simplifying rooms—for example, eliminating floor clutter and clearly identifying steps and stairways with contrasting colors, fabrics, or tape—can reduce risk of falls and hip fractures. Similarly, a brightly colored toilet seat can help the person who has difficulty seeing a white toilet against pale walls and floors. Also, leaving the bathroom door open may cue the person to enter. Large signs, pictures, or colored arrows can help people with dementia find their way around home or a facility.

INTERVENTIONS

Successful nonpharmacologic interventions are individually tailored and take into consideration a person’s needs, abilities, customs, preferences, and favorite activities.^{20, 21} Various interventions have been tried, with mixed results, in an effort to reduce behavioral symptoms. Disparate outcomes of studies are often related to the diverse symptoms seen in people with dementia, as well as study limitations. Many interventions are very effective for a subset of persons with dementia and are worthy approaches in clinical practice while additional research is being conducted. Selected interventions within three broad domains—sensory enhancement, socialization, and structured activities—are highlighted.

Sensory enhancement. Therapies that stimulate the senses, such as aromatherapy and music therapy, and those that elicit pleasant memories, such as reminiscence, have been used alone and in combination for their calming and relaxing effects. They have also been used as a form of activity.

Music. Carefully selected soothing music, based on personal preference, can reduce irritability and

PAIN MANAGEMENT AND ALZHEIMER DISEASE

It can be challenging.

Many people with Alzheimer disease are unable to report their pain. In such cases, clinicians must rely on behavioral cues. Also, each person might have a "pain signature"; if so, it can alert the clinician that there is a problem.^{1,2} For example, one person's pain may cause him to become agitated and combative, while another may withdraw. Failure to recognize and treat pain adequately can lead to sleep disturbances, malnutrition, depression, decreased mobility, nursing home placement, and needless suffering.¹

One of the most important early steps in evaluating people with Alzheimer disease is to obtain a baseline pain assessment. Changes in baseline findings are then used to determine the need for adjustments in the treatment plan, such as the addition of an analgesic or an increase in analgesic dose.

Because self-report is the single most reliable indicator of pain, those who are able to communicate verbally should be asked directly about the presence of pain.^{1,3,4} (It's recommended that a variety of simple words, such as "ache" or "sore," be used to discuss the concept of pain and that adequate time be given for responses.²) A self-reporting tool, such as a 0-to-10 or a faces pain-rating scale, should be used to determine pain intensity.

Behaviors such as crying, moaning, and groaning are commonly used to assess pain. Nonverbal expressions of pain include agitation; an increase in confusion; a decrease in mobility; combativeness; resistance to care; guarded positioning; grimacing; restlessness; changes in eating or sleeping habits; withdrawal from friends, family, or favorite activities; aggression; rubbing a particular body part; breathing heavily; and loss of function.² It's important to assess pain at rest and during activity; however, pain behaviors may be more obvious during activity, such as during repositioning.

An empiric analgesic trial is another method of assessment when pain is suspected. For example, in the presence of pathology and before, during, and after potentially painful procedures, acetaminophen can be administered in around-the-clock, scheduled doses.² Any subsequent changes in pain-related behaviors or activity indicate the need for a more thorough assessment and initiation of further pain management interventions.

The principles of good pain management in adults without Alzheimer disease apply universally to those with the disease. Nonopioid analgesics (acetaminophen and nonsteroidal antiinflammatory drugs) should be considered for mild-to-moderate pain. Opioid analgesics are added to the treatment plan for more severe pain. If neuropathic pain is suspected, adjuvant analgesics, such as local anesthetics, anticonvulsants, and antidepressants, are indicated.¹ As with all older adults receiving analgesia, the adage "start low, go slow" applies. Finally, systematic reassessment of pain will help ensure continuity and the timely recognition of the need for adjustments in the treatment plan.—*Amanda Simmons, MSN, RN, nursing instructor for the Technical College of the Lowcountry, Beaufort, SC, and Chris Pasero, MS, RN, FAAN, pain management educator and consultant in El Dorado Hills, CA*

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agitation for people with dementia at meal time and stimulate remote memory.^{22,23} How important music was to the person before cognitive impairment may be a factor in its effectiveness as an intervention.²⁴

Aromatherapy. Many nurses and other providers believe that the aromas of essential oils derived from plants or flowers, such as lemon balm, have a positive effect on mood, sleep, and stress in people with dementia.²⁵ These oils can be diffused into the air, sprinkled on bed linen, administered with a cotton ball, or combined with an odorless lotion. Aromatherapy can also be used in combination with massage or touch therapy.²⁶ A person's

response to aromas depends on the positive or negative memories the smells trigger.

Snoezelen. The Snoezelen intervention is a multi-sensory, environmental intervention designed to enhance relaxation and trust in people of all ages with many types of disabilities, including cognitive impairment. Snoezelen rooms typically have features that stimulate the senses, such as breeze machines, textured objects, colored lights, aromas, and gentle music.²⁷ Evidence of the effectiveness of the Snoezelen approach is still equivocal, but there have been reports of its helpfulness to some people with dementia.

COMBATIVENESS

Behavior: With lots of cues and encouragement, Sarah Cohen is helped to the bathroom, where her shower begins. Working as a team, the nurse and nurse's aide try to make "quick work" of an often-difficult task. Instead, they trigger an intense reaction, as water is accidentally sprayed on Ms. Cohen's face. Ms. Cohen grabs and pinches the closest caregiver as she screams in distress, then clenches her fists and begins striking out, hitting both providers.

Intervention: The nurse quickly apologizes, saying, "I'm sorry. You're safe with us. Here, hold this over your eyes," and she hands Ms. Cohen a washcloth to cover her face.

Socialization. Agitated behaviors can be reduced through the use of interventions that increase the frequency and quality of social interaction, thereby helping to decrease sensory deprivation and social isolation. These interventions include contact with people and pets and simulated interactions, both in groups and one on one.

Pets. In studies the presence of a pet has been shown to reduce agitated and aggressive behaviors in people with Alzheimer disease, and a "therapy dog" on a special care unit resulted in increased socialization (such as verbalization, smiles, looks, and touch) among residents with dementia.^{28, 29} Positive effects on caregivers have also been suggested.³⁰

Reminiscence. Nurses and family members can use sensory cues, such as a photo album, to stimulate comforting, positive, long-term memories (which are better preserved than short-term ones). Reminiscence is often used as a distraction—for example, showing someone pictures of cats that look like ones she had as a younger person as a way to calm agitation.

"*Video respite*" refers to the use of videotapes to engage the attention of persons with dementia, and in so doing to comfort and calm them and also provide respite for caregivers.³¹ Videotapes are designed to stimulate remote memories of favorite experiences, people, and objects. The tapes can be created either by family members who follow scripts using personal content or by professional actors who converse using simple, slow-paced dialogue. (See www.videorespite.com for one example). Preliminary research has found that most people with dementia can watch and participate with tapes; there is no relationship between degree of cognitive impairment and ability to respond to tapes. Viewing tapes alone instead of in groups results in more positive verbal and nonverbal responses, and overall, significant increases in positive behaviors are observed.^{31, 32}

Simulated presence therapy is designed to decrease agitation and increase social interaction by recording a personalized conversation about important memories and family anecdotes on audiotape.³³ The person listens to the tape through headphones when agitated. Family members are helped to prepare audiotapes using a conversational style and incorporating periods of silence that encourage listeners to respond and engage. Studies report positive but mixed results. Significant improvement in social isolation and declines in agitation are observed in some but not all participants, raising questions about individual characteristics (such as attachment styles) that may influence outcomes.^{34, 35}

Structured activities, which alleviate boredom and agitation in people with dementia, may be recreational (sewing, sorting) or physical (walking, movement, and exercise programs). For people with late-stage dementia and severe cognitive impairment, it can be particularly difficult to develop therapeutic activities. Buettner developed "Simple Pleasures" as an intervention for this population.³⁶ This intervention involves handmade items such as tether balls and fleece-covered hot water bottles made by families and volunteers and given to people with dementia; the goal is to improve interactions between visitors and people with dementia by giving the visitors the ability to provide something tangible that can decrease boredom and agitation. Buettner found that "the families viewed their visits much more positively during the intervention," and that "agitation levels significantly and dramatically declined." A 2002 study had similar results.³⁷ (See "Simple Pleasures," page 54.)

The family involvement in care intervention. Most family caregivers possess much information about the person's history, routines, and preferences. But when the person with dementia is relocated to a long-term care facility, family members often need help in developing a new caregiving role, one that emphasizes more indirect, supportive, and interpersonal care. The "family involvement in care intervention" was developed by Maas and colleagues to help nursing home staff and family members negotiate a partnership, in which the particular expertise of each is used to best advantage.³⁸ The intervention involves orienting the family to the facility and partnership role, negotiating a partnership contract, educating family members on involvement in care, and evaluating and renegotiating the partnership contract as needed. The intervention is associated with positive outcomes for both sets of caregivers.³⁹ Families report reduced emotional burden, while staff report reduced stress from the care recipient's behavior, and both family and staff caregivers report improved perceptions of

their relationships with one another, the care provided, and facility management.

Promotion of continuity between levels of care. Over the long and unpredictable course of most dementias, care is often provided in a variety of settings, from home to hospice. A particular challenge for nurses is continuity between levels of care. Because much relies on knowing the person's history, nurse-to-nurse exchange of information is often critical when the person is discharged or transferred from one level of care to another. For example, appropriate care plans are facilitated by—in addition to the usual medical and surgical histories—the prompt provision of consent forms signed by legal representatives, mental status assessments, personal care preferences, psychosocial and behavioral histories, and information about the person's premorbid personality characteristics.

Although staff and family caregiver training programs are needed to change attitudes and provide skills needed to care for older adults with dementia, training alone is insufficient to achieve consistent changes in practices. Among facility caregivers, the monitoring of performance, consequences for failure to use techniques, and strategies to overcome organizational resistance to change are also needed to sustain new care practices.

By focusing on the person rather than on the disease, nurses promote comfort and functional autonomy in older adults whose cognitive impairments have progressed and yet who are very much alive. t



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- outline the goals, principles, and models of dementia care.
- plan the appropriate behavioral interventions for people who have dementia.

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