Nonpharmacologic Management of Behavioral Symptoms in Dementia

Laura N. Gitlin, PhD
Helen C. Kales, MD
Constantine G. Lyketsos, MD, MHS

THE PATIENT’S STORY
Mr P is a 93-year-old bachelor who has lived in the United States since emigrating from Mexico at age 8. He began to have memory problems 13 years ago such as forgetting why he walked into a room or whether he had taken his medications. Mr P sought treatment in 2004 and scored 29 of 30 points on the Mini-Mental State Examination (MMSE; normal cognition score >24). His memory impairment, coupled with results from brain computed tomography showing white matter changes and bilateral and frontotemporal atrophy, led to diagnosis of mild cognitive impairment due to brain vascular disease.

By 2010, Mr P’s score had declined by 8 points (MMSE, 21/30) and his course of illness was considered consistent with mild progressive dementia. Mr P lives with Mr C, a cousin who is also his primary caregiver. Mr P has no children and all other family lives in Mexico. His caregiver is employed full time, which requires that Mr P stay at home alone. Mr P relies on his caregiver to organize and administer his 13 medications and to perform instrumental activities such as shopping and cooking. He dresses and bathes independently.

Mr P maintained a positive mood as his disease progressed. He lacked insight into his memory problems. Neuropsychological testing revealed major impairments in executive function, verbal and spatial memory, word-finding ability, and recall. His other diagnoses included hypertension, type 2 diabetes mellitus, lower extremity peripheral neuropathy, and coronary artery disease.

Mr P’s dementia progressed, he napped excessively during the day, experienced nighttime restlessness, and frequently awakened Mr C. Additionally, he withdrew from gardening and other previously enjoyed activities and reported feelings of insecurity and loneliness.

Behavioral symptoms such as repetitive speech, wandering, and sleep disturbances are a core clinical feature of Alzheimer disease and related dementias. If untreated, these behaviors can accelerate disease progression, worsen functional decline and quality of life, cause significant caregiver distress, and result in earlier nursing home placement. Systematic screening for behavioral symptoms in dementia is an important prevention strategy that facilitates early treatment of behavioral symptoms by identifying underlying causes and tailoring a treatment plan. First-line nonpharmacologic treatments are recommended because available pharmacologic treatments are only modestly effective, have notable risks, and do not effectively treat some of the behaviors that family members and caregivers find most distressing. Examples of nonpharmacologic treatments include provision of caregiver education and support, training in problem solving, and targeted therapy directed at the underlying causes for specific behaviors (eg, implementing nighttime routines to address sleep disturbances). Based on an actual case, we characterize common behavioral symptoms and describe a strategy for selecting evidence-based nonpharmacologic dementia treatments. Nonpharmacologic management of behavioral symptoms in dementia can significantly improve quality of life and patient-caregiver satisfaction.

Author Affiliations: Department of Community Public Health in the School of Nursing, Department of Psychiatry and Division of Geriatrics and Gerontology in the School of Medicine, and Center for Innovative Care in Aging, Johns Hopkins University, Baltimore, Maryland (Dr Gitlin); Section of Geriatric Psychiatry, Department of Psychiatry, and The Program for Positive Aging, University of Michigan, and VA Center for Clinical Management Research, and Geriatric Research Education and Clinical Center, VA Ann Arbor Healthcare System, Ann Arbor, Michigan (Dr Kales); and Department of Psychiatry, Johns Hopkins Bayview Medical Center, Baltimore, Maryland (Dr Lyketsos).

Corresponding Author: Laura N. Gitlin, PhD, Department of Community Public Health, School of Nursing, Johns Hopkins University, 525 Wolfe St, Ste 316, Baltimore, MD 21205 (lgitlin1@jhu.edu).

Call for Patient Stories: The Care of the Aging Patient editorial team invites physicians to contribute a patient story to inspire a future article. Information and submission instructions are available at http://geriatrics.medicine.ucsf.edu/agingpatient/.

Care of the Aging Patient: From Evidence to Action is produced and edited at the University of California, San Francisco, by Seth Landefeld, MD, Louise Walter, MD, Louise Avorn, MD, MFA, and Anna Chang, MD; Amy J. Markowitz, JD, is managing editor. Care of the Aging Patient Section Editor: Edward H. Livingston, MD, Deputy Editor, JAMA.
Concurrently, caregiving responsibilities increased for Mr C and he had limited outside support. He found Mr P’s confusion and repetitive questioning difficult to endure and became sleep deprived because Mr P awakened him and was “hearing voices at night.”

In 2011, paramedics brought Mr P to an emergency department after he became lost and subsequently fell. Immediately preceding this event, he was home alone and had a nosebleed. He became anxious and left the house to seek help. He was found by neighbors who phoned to alert Mr C. This caused Dr J, Mr P’s physician, to question Mr P’s decision-making capacity and ability to safely stay at home alone. A Care of the Aging Patient series editor interviewed Mr P, his caregiver, and his physician in 2011.

**Perspectives**

Mr P: (Asked about his health) . . . My heart? . . . I’m very well for my age . . . I think you have noticed I’m not hearing well . . . I’m mostly by myself. [My caregiver] goes to work during the daytime. I don’t see him . . . I just get lonesome.

Mr P’s caregiver: Well, it’s not easy. I have to be very patient and sometimes I’m not patient enough. . . . What I don’t like is [being awakened] during the night when he gets up and turns on the light in my room and he wants to know if I’m there.

Dr J: (Recalled) The patient declined in his cognitive abilities . . . In evenings, he was very restless . . . He wasn’t sleeping and was turning on lights and talking loudly . . . The caregiver was concerned because he appeared to be talking to people.

Dementia-associated behaviors worsen quality of life for patients and their family caregivers.1,2 Dementia is a pandemic that is projected to afflict more than 16 million patients in the United States by 2050.3 Most patients receive care at home from family throughout the disease course.4 As with many patients with dementia, Mr P’s behavioral symptoms (TABLE 1) evolved as his disease progressed.

**METHODS**

We searched PubMed for English-language studies in peer-reviewed journals published from January 1992 to July 1, 2012, concerning nonpharmacologic behavioral management and focused primarily on community-dwelling dementia patients. Search terms included nonpharmacologic interventions and nonpharmacologic strategies; behavioral symptoms in dementia; and neuropsychiatric symptoms, treatment for neuropsychiatric behaviors; and behavioral and psychological symptoms of dementia. We also searched for recent published systematic reviews, meta-analyses, Cochrane reviews, and home- and community-based randomized trials of nonpharmacologic treatments from January 2001 to July 1, 2012, with behavioral symptoms as an outcome. Additionally, we searched PubMed and websites of medical organizations for published dementia care guidelines that included treatment for behaviors and reviewed the Physician Consortium for Performance Improvement 2011 Dementia Performance Measurement Set. Our data synthesis and recommendations were developed using existing evidence and our clinical experience. A summary of systematic reviews and meta-analyses and additional resource websites are provided online (eTable 1, eTable 2, and eResources; available at http://www.jama.com).

**Definition, Etiology, and Prevalence of Behavioral Symptoms**

Behavioral symptoms are a heterogeneous group of noncognitive disturbances that occur in patients with dementia. These symptoms are frequently difficult to manage. In this article, behavioral symptoms refer to the psychiatric manifestations of dementia that occur in clusters (depression, psychosis, apathy [diminished motivation], agitation, aggression, delusions, hallucinations, sleep disturbances, and executive dysfunction) and other behaviors (repetitive vocalizations, shadowing, resistance to care, wandering, and argumentativeness) commonly observed in dementia.2

Behavioral symptoms are almost universally observed in dementia, regardless of the underlying etiology.2,3-9 However, some causes of dementia are frequently associated with particular behaviors. Depression is most common in vascular dementia. Hallucinations are more frequent in disseminated Lewy body disease than in Alzheimer disease. Frontotemporal dementia is often characterized by executive control loss (evidenced by behaviors such as disinhibition, wandering, social inappropriateness, and apathy).10-12 Behavioral symptoms occur at all disease stages. Depression is frequently observed in mild cognitive impairment and early-stage Alzheimer disease and may worsen with disease progression. Delusions, hallucinations, and aggression are more common in moderate to severe disease stages.2 Apathy, as occurred with Mr P, is among the most frequent and persistent behavioral symptoms across all dementia stages and is commonly reported by family members.2 Agitation, another chronic and persistent problem reported by families, involves emotional distress, excessive psychomotor activity, wandering, aggressive behaviors,2 irritability, disinhibition, and vocally disruptive behaviors.13-18 Agitation occurs at all levels of dementia severity, but particularly in middle to later stages (MMSE < 20).3,15-17

Cognitive impairment alone does not explain the etiology of abnormal behaviors. Behavioral symptoms may be caused by brain damage. Also, as patients with dementia have heightened vulnerability to their environment, behavioral symptoms may result from the confluence of multiple, some potentially modifiable, interacting factors including internal (eg, pain, fear) and/or external (eg, overstimulating environment, complex caregiver communications) features.9

Caregivers must cope with multiple behaviors simultaneously (as with Mr P). Dementia-related behaviors tend to last long periods of time but may fluctuate in frequency and severity.5,15-19

©2012 American Medical Association. All rights reserved.
Consequences of Behavioral Symptoms

Behavioral symptoms generate more harmful consequences to patients and families than symptoms attributable to memory loss from cognitive decline. Individuals with dementia, such as Mr P, typically have limited insight into their behaviors and how they impact caregivers. Caregivers for these individuals frequently have no training in how to manage these behaviors. Managing behavioral symptoms is associated with increases in health services utilization, direct care costs, and family time spent in daily oversight, as with Mr P and his caregiver.22,23

Behavioral symptoms increase risk of engagement in dangerous activities, hasten disease progression, and may result in nursing home placement, restraint use, and psychiatric admissions. Depression, delusions, agitation, hallucinations, and caregiver distress are also associated with nursing home placement. Managing a patient’s sleep disturbances, wandering, repetitive vocalizations, or other common behavioral symptoms (restlessness, anxiouslyness, overactivity, resisting or refusing care), are the most problematic and distressing aspects of care provision (as with Mr P).2,21,31,32 Caregivers of patients with behavioral symptoms are more distressed and depressed than those not managing behaviors.33

### Table 1. Potential Nonpharmacologic Strategies Targeting Mr P’s Behaviors

<table>
<thead>
<tr>
<th>Targeted Behavior by Presenting Dementia Stage</th>
<th>Select Nonpharmacologic Strategies</th>
<th>a</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild cognitive impairment</td>
<td>Forgetfulness about taking medication</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>General forgetfulness; disorientation to time</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moderate dementia</td>
<td>Failing and poor balance</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hearing voices or noises (especially at night)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inability to respond to emergency (difficulty calling for help)</td>
<td></td>
<td>Educate caregiver about need to supervise patient</td>
</tr>
<tr>
<td>Leaving the home; wandering outdoors</td>
<td></td>
<td>Outfit with an ID bracelet (eg, Alzheimer Safe Return Program) or badge with patient’s name and address</td>
</tr>
<tr>
<td>Memory-related behavior (eg, disorientation or confusion with object recognition)</td>
<td>Label needed objects</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Keep all objects for a task in a labeled container (eg, grooming)</td>
</tr>
<tr>
<td>Nighttime wakefulness, turning on lights, awakening caregiver, feeling insecure at night</td>
<td>Evaluate sleep routines</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Repetitive questioning</td>
<td>Respond using a calm, reassuring voice</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

aStrategies are potential approaches used in randomized clinical trials but are not exhaustive. A suggested strategy may be effective for one patient but not another. Any single strategy may not have been evaluated for effectiveness for use with all dementia patients with the same presenting behavior. These strategies should only be considered once a thorough assessment has been completed (Figure, steps 2 and 3).

bStrategies discussed, considered, or implemented by Mr P’s physician and caregiver.
Nonpharmacologic approaches include targeted and generalized treatments (Table 1, Table 2). Nonpharmacologic approaches conceptualize behavioral symptoms as expressions of unmet needs (eg, repetitive vocalizations for auditory stimulation); inadvertently reinforced behavior in response to environmental triggers (eg, patient learns screaming attracts increased attention); and/or consequences of a mismatch between the environment and a patient’s abilities to process and act upon cues, expectations, and demands.32

Treatment goals of nonpharmacologic approaches include preventing, managing, reducing, or eliminating behavioral occurrences; reducing caregiver distress; and/or preventing adverse consequences (harm to caregiver or patient). Numerous guidelines recommend nonpharmacologic approaches as the preferred first-line treatment, except in emergency situations when behaviors lead to imminent danger to the patient or caregiver.41-43 Emerging evidence supports nonpharmacologic approaches as part of standard, comprehensive dementia care.

INTEGRATING NONPHARMACOLOGIC APPROACHES INTO DEMENTIA CARE

The Figure displays an approach involving 6 progressive, interrelated, and often concomitant steps for nonpharmacologic management of behavioral symptoms.

Screen for Behavioral Symptoms and Take Preventive Actions

Dr J: I would follow [up] his Mini-Mental State Exam once a year. . . . I mostly asked about his functioning. Initially, he would come into the clinic alone . . . then it was his caregiver and I would ask both: “What’s a normal day for you, how are things going? Any problems, any disruptive behaviors, any concerns?”

The initial management step is screening for behaviors and implementing preventive actions (Figure, step 1).41 This step uncovers the risk for developing behaviors or identifies behaviors at an early stage. There is no universally accepted standard for screening behavioral symptoms. The Physician Consortium for Performance Improvement Dementia Performance Measurement Set recommends proactive yearly screening for behaviors using a reliable and validated instrument (eg, Neuropsychiatric Inventory, its clinician version, or its shortened version).41,48,49

When behaviors are not present on screening, preventive measures may be in order and include counseling caregivers about (1) dementia, behavioral symptoms, and resources (eResources); (2) the importance of early detection of behavioral problems and physician notification; (3) patient needs for adequate stimulation and structured daily routines; and (4) the importance of self-care (eBox 1). Behavioral risk factors include caregiver distress, and for the patient, pain, sleep disturbance, inadequate nutrition, infection, or other acute medical illnesses.50,51 Evaluation of these features is important.

Describe Presenting Behaviors

Mr P’s caregiver: He would hear sounds . . . he would call me [at night at home] and ask me if I heard a sound. I told him there was no sound and maybe he was hearing something . . . That’s what I mentioned to Dr J."

When behaviors are present, clinicians should proceed with formal assessments. This involves interviewing the caregivers about (1) dementia, behavioral symptoms, and resources (eResources); (2) the importance of early detection of behavioral problems and physician notification; (3) patient needs for adequate stimulation and structured daily routines; and (4) the importance of self-care (eBox 1). Behavioral risk factors include caregiver distress, and for the patient, pain, sleep disturbance, inadequate nutrition, infection, or other acute medical illnesses.50,51 Evaluation of these features is important.

Table 2. General Nonpharmacologic Strategies for Managing Behavioral Symptoms

<table>
<thead>
<tr>
<th>Domain</th>
<th>Key Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Activities</td>
<td>Introduce activities that tap into preserved capabilities and previous interests</td>
</tr>
<tr>
<td></td>
<td>Introduce activities involving repetitive motion (washing windows, folding towels, putting coins in container)</td>
</tr>
<tr>
<td></td>
<td>Set up the activity and help patient initiate participation if necessary</td>
</tr>
<tr>
<td>Caregiver education</td>
<td>Understand that behaviors are not intentional</td>
</tr>
<tr>
<td></td>
<td>Relax the rules (eg, no right or wrong in performing activities/tasks as long as patient and caregiver are safe)</td>
</tr>
<tr>
<td></td>
<td>Consider that with disease progression, patient may have difficulty initialing, sequencing, organizing, and completing tasks without guidance and cueing</td>
</tr>
<tr>
<td></td>
<td>Concur with patient’s view of what is true and avoid arguing or trying to reason or convince</td>
</tr>
<tr>
<td></td>
<td>Take care of self; find opportunities for respite; practice healthy behaviors and attend preventive physician visits</td>
</tr>
<tr>
<td></td>
<td>Identify and draw upon a support network</td>
</tr>
<tr>
<td>Communication</td>
<td>Allow patient sufficient time to respond to a question</td>
</tr>
<tr>
<td></td>
<td>Provide 1- to 2-step simple verbal commands</td>
</tr>
<tr>
<td></td>
<td>Use a calm, reassuring tone</td>
</tr>
<tr>
<td></td>
<td>Offer simple choices (no more than 2 at a time)</td>
</tr>
<tr>
<td></td>
<td>Avoid negative words and tone</td>
</tr>
<tr>
<td></td>
<td>Lightly touch to reassure, calm, or redirect</td>
</tr>
<tr>
<td></td>
<td>Identify self and others if patient does not remember names</td>
</tr>
<tr>
<td></td>
<td>Help patient find words for self-expression</td>
</tr>
<tr>
<td>Simplify environment</td>
<td>Remove clutter or unnecessary objects</td>
</tr>
<tr>
<td></td>
<td>Use labeling or other visual cues</td>
</tr>
<tr>
<td></td>
<td>Eliminate noise and distractions when communicating or when patient is engaging in an activity</td>
</tr>
<tr>
<td></td>
<td>Use simple visual reminders (arrows pointing to bathroom)</td>
</tr>
<tr>
<td>Simplify tasks</td>
<td>Break each task into very simple steps</td>
</tr>
<tr>
<td></td>
<td>Use verbal or tactile prompt for each step</td>
</tr>
<tr>
<td></td>
<td>Provide structured daily routines that are predictable</td>
</tr>
</tbody>
</table>

*Strategies are potential approaches used in randomized clinical trials but are not exhaustive. A suggested strategy may be effective for one patient but not another. Any single strategy may not have been evaluated for effectiveness for use with all dementia patients with the same presenting behavior. These strategies should only be considered once a thorough assessment has been completed (Figure, steps 2 and 3).
Figure. Screening, Identifying, and Managing Behavioral Symptoms in Patients With Dementia

**STEP 1**
Are behavioral symptoms occurring?
Screen for behavioral symptoms using standardized tool (e.g., NPI-Q)
Involve key informant

Yes

**STEP 2**
What do behavioral symptoms look like?
Describe behavioral symptoms and involve key informant

Are behavioral symptoms sudden or recent onset?
Are there a safety concern?
Is caregiver distressed?

Yes

**STEP 3**
What are underlying causes?
Identify potential modifiable triggers of behavioral symptoms

**STEP 4**
What is the treatment plan?

Develop treatment plan

If targeting 1 behavior
Identify and eliminate modifiable triggers (see Table 1)

If targeting multiple behaviors
Use generalized approach (e.g., exercise, activities and pleasant events, caregiver education, skills training, environmental simplification, structuring daily routines) (see Table 2)

Consider referral to specialist

**STEP 5**
Are recommendations effective?
Evaluate if plan eliminates or manages behavioral symptoms

Yes

No

**STEP 6**
Are new behavioral symptoms emerging?
Ongoing monitoring; reassess for new behavioral symptoms, safety, caregiver distress, and nonpharmacologic strategy use

1. Continue monitoring (follow PCPI schedule)
2. Educate caregiver (see eBox 1)
3. Minimize risk factors for behavioral symptoms (e.g., caregiver distress, patient pain, unmet needs)

1. Rule out and treat underlying medical illness
2. Review medications
3. Evaluate for and manage pain, nutrition, constipation, hydration, sleep

1. Recommend safety strategies
2. Educate caregiver
3. If safety not improved, refer to specialist or admit

1. Educate caregiver
2. Screen for depression
3. Recommend stress-reduction strategies
4. If distress not improved, refer to specialist

1. Problem solve with key informant
2. Revise recommendations
3. Refer to specialists or other team members depending on the reason strategy was not implemented or implemented ineffectively (e.g., caregiver too depressed to implement strategy)

NPI-Q indicates Neuropsychiatric Inventory Questionnaire; PCPI, Physician Consortium for Performance Improvement.

Key informant may or may not be the caregiver.

Consider referrals to Alzheimer's Association for support groups, education, other services; geropsychiatrist for difficult to manage cases, when medications may be needed; occupational therapist for driving evaluation, caregiver skills training, environmental modification, activity programming, functional improvement, home safety evaluation and risk reduction; physical therapist for exercise, mobility and balance, fall risk reduction; social worker for care coordination, caregiver counseling, support, and skills training; nurse for medication and physical health monitoring, caregiver training.
tient and caregiver to characterize behaviors and the circumstances of their occurrences (Figure, step 2). Differentiating behavioral symptoms is important. For example, agitation encompasses varied behaviors and may involve physical (hitting, pacing, biting, pushing), verbal (threats, screams), and/or passive (withdrawal, handwringing, blank stare) attributes that should be delineated to derive specific treatment approaches.

Clinicians should consider behaviors from the patient’s perspective. However, with disease progression, the patient may be unable to accurately remember behaviors or will not comprehend risks for his/her safety; thus caregiver involvement becomes essential (eBox 2). Safety and the level of caregiver distress are important to establish when evaluating behaviors (eTable 3). As patients become more impaired, they need more supervision to remain safe. Referral to an occupational therapist for a comprehensive home safety evaluation is appropriate. Safety concerns for Mr P included being home alone while his caregiver worked and his inability to respond effectively in emergency situations. Mr P’s complaint of nighttime noises put his caregiver at risk for sleep deprivation and resulting poor work performance.

As safety became an increasing concern, Dr J spent more time educating the caregiver regarding Mr P’s declining capabilities, his increasing need for daily oversight, and care alternatives that would prevent him from remaining at home alone.

Determining the caregiver’s burden level is important when evaluating the urgency of modifying a patient’s behavior(s). Caregivers may feel that the patient’s behavior is intended “to bother them.” eBox 3 provides questions to help discern caregiver distress. A depressed caregiver can benefit from referral to a psychiatrist or psychologist for evaluation and counseling, psychotherapy, or antidepressant medication.

Identify Underlying Causes

Dr J: Any time someone comes to me with . . . a change in behavior, I . . . hope it wasn’t something I did. I look at the medications. Basically, I want to make sure that the patient is not delirious. Does the patient have a urinary tract infection or . . . [was there] . . . a medication change? As far as him hearing things, I became suspicious when he was trying to describe what he was hearing. He had bilateral hearing aids and I was wondering if they were just amplifying all of these sounds . . . we sent him to audiology and they adjusted his hearing aids . . . he has not had any further auditory hallucinations.

Step 3 (Figure) is to find possible causes for identified behaviors (eBox 4). When there is a sudden or recent onset of behavioral symptoms, the contribution of patient-related factors such as medical illness, pain, or medications must be determined. Dr J did consider hearing loss as an issue since it is a risk factor for delusions and hallucinations. Dr J established that depression and medical conditions were not responsible for Mr P’s behavioral changes.

Dr J: The caregiver has done an amazing job. . . he’s able to answer the patient calmly when he’s repeating things. . . the disruption in sleep and auditory hallucinations . . . set the family on edge and the caregiver was just overwhelmed.

Certain caregiver behaviors can have a negative influence on patient behaviors. Clinicians should observe the caregiver’s coping and communication styles, closeness to the patient, and access to support (eBox 4) to encourage more caregiver/patient satisfaction. Negative communicating (yelling, use of harsh tone, criticizing) is associated with increased patient agitation, and dysfunctional coping (eg, problem will go away if ignored) is associated with poorer patient outcomes; whereas problem-solving coping (eg, proactive, task-focused) and a close relationship with the patient, which are associated with better patient outcomes.

Dr J: . . . state funding for adult day [services], things that could help [Mr P] be safer and which he would really enjoy, has been cut . . . 

Financial constraints may compromise use of some non-pharmacologic approaches or contribute to caregiver burden. As financial strain and caregiver burden are predictive of nursing home placement, it is essential to recognize these and other contextual factors and to work with families to address them.

The home environment should be evaluated to determine if it is contributing to problem behaviors. This assessment can be facilitated by occupational therapists via key informant interviews or direct observation. Factors may include the presence of excessive stimulation (noise, number of people, clutter), understimulation (no objects to view or touch, poor lighting), uncomfortable room temperature, and way-finding challenges (difficulties locating bathroom, bedroom, kitchen).

Devise a Treatment Plan

A treatment plan (Figure, step 4) may include generalized and/or targeted behavior-specific approaches. Based on evidence from randomized controlled trials, effective generalized approaches include use of structured activity, caregiver education and skills training, and adult day services (Table 2).

Mr P: I don’t do exercise . . . mostly I do a little gardening . . . The rest of the time I read the paper or watch TV . . . oh, I can walk more than 2 or 3 blocks. I do a lot of walking.

Activity. Some cases of patient depression can be reduced by a combination of physical exercise and caregiver training in behavioral management techniques, although the specific dose, intensity, and type of exercise maximizing benefit are unclear. Simple activities such as accompanied daily walks can enhance feelings of well-being and improve sleep. Purposeful activities (social, cognitive, physical) with intrinsic meaning to the patient and graded to the patient’s capabilities can reduce agitation and other disruptive behaviors. For example, a patient with moderate dementia with a previous interest in fishing may be able to
organize a tackle box and sort plastic equipment (lures, weights); or in the moderate-severe stage, look through a fishing magazine or watch a video on fishing.65,66

Mr P’s caregiver: I think it would be very advisable to have some classes that people can go to in order to really understand the situation.

Caregiver Interventions. A meta-analysis of 23 randomized clinical trials provides strong confirmation of the benefits of caregiver interventions for reducing behavioral symptoms. Collectively, these trials involved 3279 community-dwelling caregivers and patients. Significant treatment effects were demonstrated for reducing behavioral symptoms (effect size, 0.34; 95% CI, 0.20-0.48) and caregiver negative reactions (effect size, 0.15; 95% CI, 0.04-0.26).63 Even small improvements can make a critical difference in helping patients to continue living at home.

These interventions varied in dose, intensity, and delivery mode (telephone, mail, face-to-face, groups, computer technologies); however, patient- and caregiver-centered initiatives, tailored to the challenges families identified as troublesome, involving disease education and skills training (problem solving, communication strategies), social support, and/or environmental modifications (assistive device use) were most effective.65

Although these interventions are not widely available yet and can be time consuming, it is possible to implement these approaches in primary care by involving nurses or other staff who can meet with caregivers during patient encounters.67 Alternately, referral to local Alzheimer’s Associations may be helpful. Some branches offer caregiver interventions and group support.

Dr J: . . . Another option would be referring somebody to adult day [services] every day— which this patient would really enjoy. . . . it takes the burden off of the caregiver by having other people watch the patient.

Adult Day Services. A systematic review of studies on adult day services shows multiple benefits including reductions in behavioral symptoms and caregiver distress.68,69 However, level of exposure for symptom reduction is unclear and outcomes may be patient-specific.

Other Generalized Strategies. Music interventions ranging from listening to recorded music or music activities in individual or group settings are promising.70 Musical abilities appear preserved in some patients. A few randomized trials found reduced aggression, agitation, and wandering while patients were engaged in music.70

There is inconsistent to no evidence supporting reminiscence therapy (discussion of past experiences), validation therapy (work-through unresolved conflicts), simulated presence therapy (use of audiotapes by family members of patient’s life), aromatherapy (use of fragrant plant oils), or light therapy in reducing behavioral symptoms.70,71 There are no high-quality studies of acupuncture (eTable 1, eTable 2).

TARGETED APPROACHES
Mr P’s caregiver: . . . he was afraid to sleep by himself and he wanted me to sleep with him . . . he needed the lights to be on during the whole night because he was afraid. He didn’t feel secure. I decided to buy one of those lights that you keep on all night, and it’s working.

A targeted approach involves implementing specific strategies directed at a single behavior (eg, agitation when bathing). Problem-solving to identify precipitating and modifiable causes and consequences of the identified behavior are followed by efforts to modify these conditions (eg, ensuring that the bathroom is warm and the water temperature is not too hot). This approach relies on a key informant (family member) who works with the clinician to characterize the behavior and help identify modifiable factors and strategies (Figure, steps 2 and 3).

A targeted approach would be useful for Mr P’s sleep disturbance. It would first involve ruling out depression and other causes, examining the physical environment where he sleeps, and assessing his daily and bedtime routines (Figure, steps 2 and 3). A home evaluation of sleeping quarters and nighttime routines could provide important information for devising a treatment plan. Based on identifying contributing factors to the behavior, potential strategies might include eliminating caffeinated beverages, afternoon napping, and stimulating environmental distractions (television at bedtime); and implementing a structured daily routine of exercise, meaningful activity, a structured nighttime routine possibly involving soft music, and otherwise setting a tranquil tone.

A randomized trial with 272 community-dwelling patients and their caregivers showed that targeting behaviors most distressful to caregivers and modifying potential triggers improved or eliminated patient symptoms and enhanced caregiver well-being and skills.32 The Resources for Enhancing Caregiver Health initiative (REACH II) involving 642 diverse families demonstrated that a targeted problem-solving behavior approach combined with other caregiver support strategies (eg, generalized approach) effectively reduced behavioral symptoms and caregiver distress.57

Few studies have been conducted that target specific behaviors in community-dwelling patients. For wandering, 4 systematic reviews of nonpharmacologic strategies found no evidence of benefit from exercise or walking therapies in randomized trials.70 For aggression,6,72 educating caregivers in strategies such as distracting the patient, backing away, and leaving the room (if patient is safe) have been reported to be helpful. Studies of nursing home residents suggest that personalizing the bathing experience (eg, offering choice, creating a spa experience)73 can minimize agitation and aggression.
Determine Effectiveness of Nonpharmacologic Strategies

Dr J: The sleep problems persist... We were trying to think of all the different angles. He wasn’t depressed... he wasn’t in pain. We worried that his vision was poor, so we had him see the eye doctors. We had him put in a nightlight so he wouldn’t flip on all the lights for the whole family... we talked about the whole idea of good sleep hygiene. The patient had been drinking a fair amount of caffeinated beverages and I think he normally had a glass of wine at night. We had been tapering down on those things. He was in a quiet place... he was just laying around the house and napping a lot. So, getting him out of the house and into a senior center was another remedy that we came up with and that actually worked pretty well. On the days that he went to the senior center, he slept pretty well at night.

Step 5 (Figure) involves evaluating the effectiveness of the treatments used to resolve the behavior. If there are no behavioral improvements, it is important to determine if characteristics of the behavior, the patient’s environment, or health status changed; if the strategy lacked effectiveness; or how the caregiver implemented strategies.

Dr J tried various strategies until resolution was obtained for Mr P’s sleeplessness. If resolution is not obtained, other treatment options such as referral to specialists should be considered.

Ongoing Monitoring

Ongoing monitoring of behaviors (Figure, step 6) is essential to implementing and adjusting appropriate nonpharmacologic treatments. The Figure shows that the treatment cycle may repeat as behaviors change and its steps reflect a repetitive cycle that are adjusted as the patient’s behavioral symptoms fluctuate or change.

ADVERSE EFFECTS

Nonpharmacologic strategies do not carry the level of risk associated with pharmacologic treatments. However, potential for adverse effects should not be ignored. A few studies report increased agitation in cognitive/emotion-oriented interventions. Increased agitation and physical aggression have also been reported for some sensory approaches (music therapy, massage/touch therapies, aromatherapy).

Challenges

One challenge is that our framework may be labor intensive. Reimbursement and care systems do not adequately support nonpharmacologic therapies. Busy clinicians may find it challenging to integrate the 6 steps over short patient visits. However, forming a dementia team with other health professionals may address this challenge. Another challenge is that nonpharmacologic strategies may be effective for certain symptoms (repetitive questioning, agitation), but not others (hallucinations). It is also unclear how nonpharmacologic and pharmacologic approaches may augment each other.

CONCLUSIONS

Behavioral symptoms are a major source of disability, making their clinical management critically important. Unfortunately, most patients treated in primary care do not receive thorough assessment, treatment, and monitoring of behavioral symptoms. Mr P experienced behavioral symptoms such as hearing voices at night, which often trigger a physician’s prescription for antipsychotic medications. However, as illustrated, nonpharmacologic strategies including evaluating Mr P’s hearing and providing hearing aids effectively managed his sleep disturbance without drug use.

There is strong evidence for using both generalized and targeted nonpharmacologic treatments. Essential to a nonpharmacologic approach is educating caregivers in ways to effectively prevent and manage behavioral symptoms. Because nonpharmacologic approaches yield high levels of patient and caregiver satisfaction, quality of life improvements, and reduced behavioral symptoms with minimal risk and adverse reactions, they should be part of standard dementia care.

Conflict of Interest Disclosures: All authors have completed and submitted the ICMJE Form for Disclosure of Potential Conflicts of Interest. Dr Gitlin reports serving as a member on the Fall Advisory Committee for Phillips Lifeline. Dr Lyketsos reports receipt of grant support (research or CME) from the National Institute of Mental Health (NIMH), the National Institute on Aging (NIA), Associated Jewish Federation of Baltimore, Weinberg Foundation, Forest, GlaxoSmithKline, Eisai, Pfizer, AstraZeneca, Lilly, Ortho-McNeil, Bristol-Myers, Novartis, the National Football League (NFL), Elan, and Functional Neuromodulation Inc; serving as consultant/advisor for AstraZeneca, GlaxoSmithKline, Eisai, Novartis, Forest, Supernus, Adlyte, Takeda, Wyeth, Lundbeck, Merz, Lilly, Pfizer, Genentech, Elan, NFL Players Association, NFL Benefits Office, Avanir, Zinfandel; and receipt of an honorarium or travel support from Pfizer, Forest, GlaxoSmithKline, and Health Monitor. Dr Kales reports no disclosures.

Funding/Support: Dr Gitlin has been supported for research reported in this article, in part, by funds from the NIA and the National Institute on Nursing (research grant R01 AG22254), the NIA (research grant R01AG041781-01A), the Pennsylvania Department of Health Tobacco Settlement (SAP 100027298), NIMH (grant R21 MH69425), and the Alzheimer’s Association (grant NPSA5-10-174265). Dr Lyketsos was supported by the Johns Hopkins Alzheimer’s Disease Research Center (PSO-AG059146). The Care of the Aging Patient series is made possible by funding from The SCAN Foundation.

Role of the Sponsors: Funding agencies did not have a role in the design and conduct of the study; collection, management, analysis, and interpretation of the data; and preparation, review, or approval of the manuscript.

REFERENCES

8. Lyketsos CG. Neuropsychiatric symptoms (behavioral and psychological symp-
CARE OF THE AGING PATIENT


©2012 American Medical Association. All rights reserved.


