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Managing Behavioral Symptoms in Dementia Using Nonpharmacologic Approaches: An Overview

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Abstract

Behavioral symptoms such as repetitive statements and questions, wandering, and sleep disturbances are a core clinical feature of Alzheimer disease and related dementias, affecting patients and their families. These behaviors have devastating effects. If untreated, they can contribute to more rapid disease progression, earlier nursing home placement, worse quality of life, accelerated functional decline, greater caregiver distress, and higher health care utilization and costs. Patients with dementia are typically not screened for behavioral symptoms in primary care and even when clinically reported, tend to receive ineffective, inappropriate, and fragmented care. Yet, clinicians are often called upon to address behaviors that place the patient or others at risk or which families encounter as problematic. It is important to include on-going systematic screening for behavioral symptoms to facilitate prevention and early treatment as part of standard comprehensive dementia care. When identified, behaviors should be characterized and underlying causes sought in order to derive a treatment plan. Because available pharmacologic treatments used to treat behaviors have modest efficacy at best, are associated with notable risks, and do not address behaviors most distressing for families, nonpharmacologic options are recommended as first-line treatments or if necessary, in parallel with pharmacologic or other treatment options. Nonpharmacologic treatments may include a general approach (caregiver education and training in problem solving, communication and task simplification skills, patient exercise, and/or activity programs), or a targeted approach in which precipitating conditions of a specific behavior are identified and modified (eg, implementing nighttime routines to address sleep disturbances). Using the case of Mr A, we characterize common behavioral symptoms of dementia and describe an assessment strategy for selecting evidence-based nonpharmacologic treatments. We highlight the clinician's important role in facilitating collaboration with specialists and other health care professionals to implement nonpharmacological treatment plans. Substantial evidence shows that nonpharmacologic approaches can yield high levels of patient and caregiver satisfaction, quality of life improvements, and reductions in behavioral symptoms. Although access to nonpharmacologic approaches is currently limited, they should be part of standard dementia care.

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The Patient's Story

Mr A is a 93-year-old man who immigrated to the United States from Mexico at 8 years of age. He lives at home with his cousin and primary caregiver, Mr Z. His other family members live in Mexico. He was a military clerical worker in the United States Army and never married or had children. About 13 years ago, Mr A complained of memory problems including forgetting why he walked into a room, or whether he had taken his medications.

An initial examination in 2004 revealed a Mini Mental State Examination (MMSE) score of 29/30, above the standard cut-off of 24 indicating concern for dementia. However, in the context of memory impairment and a head CT showing significant white matter changes and bilateral and frontotemporal atrophy, Mr A was diagnosed with possible mild cognitive impairment. His physician thought this could be a result of brain vascular disease, although Alzheimer's disease was also a possible etiology.

By 2010, the MMSE declined to 21/30. As laboratory test results indicated no potentially reversible etiology, his course was considered consistent with mild progressive dementia. Mr A was, by now, more reliant on his cousin to take medications and perform instrumental activities (shopping, cooking), although when home alone, he was able to call his cousin at work and perform self-care (dressing, bathing) independently. As the disease progressed, his mood remained positive and he lacked insight into his memory problems. Neuropsychological testing revealed major impairments in executive function, verbal/spatial memory, recall, and language, with mild word finding difficulty. He also has multiple comorbidities (hypertension, chronic hypokalemia, type 2 diabetes mellitus, lower extremity peripheral neuropathy, coronary artery disease), receives vitamin B₁₂ injections monthly and takes 13 medications.

Initially, memory-related problems were most bothersome to Mr A, whereas repetitive questioning was troublesome to his caregiver, Mr Z. In 2010, significant neuropsychiatric symptoms and behaviors (referred to as behavioral symptoms in this article) that were problematic to the caregiver emerged. The initial chief complaint to the physician, Dr J, was Mr A "hearing voices at night" and not letting Mr Z sleep. In addition to night-time hallucinations, Mr A experienced other behaviors including napping excessively during the day, withdrawing from activity, restlessness at night and waking his caregiver, and displaying feelings of insecurity and loneliness.

With dementia progression, Mr Z assumed more hands-on care responsibilities juggling full-time employment, sleep deprivation, and a limited support network. A concern to Dr J was Mr A's reduced decision-making capacity and questionable ability to stay at home alone safely. This concern was precipitated by an incident in 2011. Mr A, upon developing a nosebleed, left his home to find help, became lost, and fell. Neighbors called Mr Z and paramedics to take him to an emergency department.

A Care of the Aging Patient series editor interviewed Mr A, Mr Z, and Dr J in 2011.

Perspectives

Mr A: (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. [Mr Z] goes to work during the daytime. I don't see him ... I just get lonesome.*

Mr Z: *Well, it's not easy. I have to be very patient and sometimes I'm not patient enough. ... what I don't like is 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: *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....*

Mr A's story exemplifies a common scenario confronted by the 5.4 million people in the United States aging with dementia and complex comorbidities. Dementia-associated behavioral symptoms and their potentially devastating consequences worsen quality of life for patients and their over 15 million family caregivers.^{1,2} Considered a pandemic, dementia is projected to afflict over 115.4 million new patients worldwide and 16 million in the United States by 2050.³ Most patients are cared for at home by family throughout the disease course.⁴ As with many patients with dementia, Mr A developed behavioral symptoms (Table 1) that changed with disease progression and required ongoing interventions by his family and physician to manage.

Using Mr A's story, we describe common behaviors associated with dementia and the role of nonpharmacologic treatments including a review of existing evidence. We present a framework for integrating evidence-based nonpharmacologic treatments in dementia care involving 6 interrelated steps: routine screening for prevention or early detection of behaviors, describing presenting behaviors, identifying underlying causes, developing nonpharmacologic treatment plans, evaluating if nonpharmacologic recommendations are effective, and conducting on-going monitoring of behaviors and nonpharmacologic strategy use (Figure 1). This framework offers primary care doctors a way to effectively integrate nonpharmacologic approaches into their daily practice.

Methods

We conducted PubMed searches to identify studies in peer-reviewed journals published from 1992 to 2012 concerning nonpharmacologic behavioral management, focused primarily on community-dwelling dementia patients. Search terms included: nonpharmacologic interventions, nonpharmacologic strategies; behavioral symptoms in dementia; neuropsychiatric symptoms, treatment for neuropsychiatric behaviors, and behavioral and psychological symptoms of dementia. Studies were limited to the English language. We also searched for recent published systematic reviews, meta-analyses, Cochrane reviews, and home and community-based randomized trials of nonpharmacologic treatments from 2001 to the present with behavioral symptoms as an outcome. Additionally, we searched for published dementia care guidelines that included treatment for behaviors in PubMed, websites of medical organizations, and reviewed the Physician Consortium for Performance Improvement (PCPI) 2011 Dementia Performance Measurement Set. Our data synthesis and recommendations were informed by existing evidence, our clinical practices and trial experience testing nonpharmacologic approaches.

Definition, Etiology and Prevalence of Behavioral Symptoms

A heterogeneous group of non-cognitive manifestations occurring in patients with dementia, behavioral symptoms represent one of the most significant clinical dimensions of the disease. Various terms refer to these behaviors. Neuropsychiatric symptoms refer broadly to the cognitive, behavioral and psychological sequelae of brain diseases,⁵ and more narrowly to behavioral and psychological sequelae only,⁶ also known as *behavioral and psychological symptoms of dementia*. In this article, we use the term behavioral symptoms both to describe psychiatric manifestations of dementia (depression, apathy, agitation, delusions, hallucinations), and common behaviors that are often challenging to families (repetitive vocalizations, shadowing, resistance to care, wandering, argumentativeness).

Behavioral symptoms tend to occur in clusters or syndromes (depression, psychosis, agitation, aggression, apathy, sleep disturbances, executive dysfunction).^{2,7} As cognitive impairment alone does not explain the etiology of behaviors, further study is underway to understand phenotype and pathogenesis. They are now considered central consequences of the diffuse brain damage that brings about cognitive and functional decline in dementia. As dementia patients experience heightened vulnerability to their environment, behavioral symptoms may result from the confluence of multiple, some potentially modifiable, interacting factors including internal (e.g., pain, fear) or external (e.g., over-stimulating environment, complex caregiver communications) features.^{6,7}

Although behavioral symptoms occur at any disease stage, some appear more often than others at different stages. Depression and apathy are frequently observed in mild cognitive impairment and early stage Alzheimer's disease, and may increase in frequency as dementia worsens. Delusions, hallucinations, and aggression are more common in moderate to severe stages.² Apathy, a common family complaint, is among the most frequent and persistent behavioral symptom across all dementia stages. Defined as diminished motivation for at least 4 weeks, it is accompanied by any 2 of the following: reduced goal-directed behavior, goal-directed cognitive activity, and emotions.² Agitation, another chronic and persistent problem to families, refers to a syndrome involving emotional distress, excessive psychomotor activity, wandering, aggressive behaviors,⁸ irritability, disinhibition, and/or vocally disruptive behaviours.^{6,9} It occurs at all levels of dementia severity, but particularly in middle to later stages (e.g., MMSE <20).¹⁰⁻¹³

Behavioral symptoms are nearly universal in dementia regardless of underlying etiology.^{2,8,13-16} However, dementia due to certain etiologies may have higher rates of particular behavioral symptoms. Depression is most common in vascular dementia; hallucinations are more frequent in disseminated Lewy body disease than Alzheimer's disease; and Frontotemporal dementia is often characterized by executive control loss, evidenced by such behaviors as disinhibition, wandering, social inappropriateness, and apathy.¹⁷⁻¹⁹

Behavioral symptoms frequently co-occur, and can be a "moving target" over time. For example, wandering may be followed by delusions, which may be replaced by aggression and so on. Families frequently manage multiple behavioral symptoms simultaneously as with Mr A. While fluctuations in frequency and severity occur, behaviors tend to endure, with most persisting for at least 6 months if untreated.^{10-12,14,20,21}

Consequences of Behavioral Symptoms

Consequences of behaviors are more harmful than those attributable to cognitive decline such as forgetfulness and memory loss, and should not be underestimated.^{6,15,22,23}

Behavioral symptoms can be extremely stressful to caregivers, most of whom have little or no formal training in addressing the unique challenges symptoms usually present. Adding to complexity, persons with dementia, as reflected in Mr A, typically have limited insight concerning their behaviors or repercussions for their caregivers, although reasons for anosognosia differ by dementia type.

Behavioral symptoms heighten patient risk of engagement in dangerous activities, hasten disease progression, and are associated with restraint use, nursing home placement, and psychiatric admissions.^{8,24-28} Depression, delusions, agitation, hallucinations and caregiver distress are in particular associated with nursing home placement.^{29,30} In addition to leading to patient suffering, managing behaviors, such as Mr A's sleep disturbances, wandering, repetitive vocalizations, or other common symptoms (restlessness, anxiousness, overactivity, resisting or refusing care), are the most problematic and distressing aspect of providing

care.^{2,23,31,32} Caregivers of patients with behavioral symptoms are more distressed and depressed than those not managing behaviors.³³ Managing behavioral symptoms is one of the most costly aspects of care provision, associated with increased health utilization, direct care costs, and family time spent in daily oversight, as with Mr A and Mr Z.^{34,35}

What are Nonpharmacologic Approaches?

Typical efforts to manage behaviors involve pharmacologic treatments (specifically off label use of atypical antipsychotics), yet these show only modest improvements or no benefits compared with placebo,³⁶⁻³⁸ and evidence of adverse effects, including heightened risk for mortality.^{39,40} This has resulted in FDA warnings and an increased interest in nonpharmacologic strategies.

Nonpharmacologic treatments, defined for what they are not (not medications), refer to a broad spectrum of approaches involving some action with the patient and/or their physical and social environment. They can be broadly categorized as generalized (behavior non-specific such as caregiver education and support), or targeted (behavior-specific such as eliminating conditions contributing to a specified behavior). Either approach may directly involve the patient (e.g., exercise) and/or work through another agent—typically the caregiver (e.g., use of communication techniques) or physical environment (e.g., soothing music). Nonpharmacologic approaches conceptualize behavioral symptoms as expressions of unmet needs (e.g., repetitive vocalizations for auditory stimulation); inadvertently reinforced behavior in response to environmental triggers (e.g., patient learns screaming attracts increased attention); and/or consequences of a mismatch between the environment and patients' abilities to process and act upon cues, expectations and demands.⁴¹ Approaches may involve modifying patient and/or caregiver cognitions, behaviors, environments, or precipitating events contributing to behaviors or instructing in compensatory strategy use to reduce the patient's increased vulnerability to their environment.

Treatment goals of nonpharmacologic approaches include prevention, management, reduction, or elimination of behavioral occurrences (frequency, severity); reduction of caregiver distress; and/or prevention of adverse consequences (harm to caregiver or patient). Guidelines from medical organizations and working groups recommend nonpharmacologic approaches as the preferred first-line treatment, except in emergency situations where behaviors lead to imminent danger to patient or caregiver, and/or which require hospitalization.⁴²⁻⁴⁸ Emerging evidence coupled with practical know-how supports their use as part of standard, comprehensive dementia care.

Integrating Nonpharmacologic Approaches into Dementia Care

Figure 1 displays a decision-making approach involving 6 progressive, highly interrelated and often co-occurring steps for managing behavioral symptoms nonpharmacologically.

Screen for and Prevent Behaviors (Figure 1–Step1)

Dr J: *I would follow 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 step is assuming a preventive stance by conducting on-going systematic screening for behaviors and implementing preventive actions.⁴² By doing so, behaviors are less likely to occur and can be identified early and treated immediately, leading to harm avoidance and better management.

There is no widely agreed upon standard for screening behavioral symptoms. Behaviors are typically brought to a physician's attention by a concerned caregiver or other healthcare provider after their occurrences. The PCP's I Dementia Performance Measurement Set suggests that screening occur proactively and at minimum, yearly, using a reliable and validated instrument (e.g., Neuropsychiatric Inventory (NPI), its clinician (NPI-C) or shortened versions (NPI-Q)).^{42,49,50}

Based on screening, when behaviors are not present, critical preventive measures may include counseling caregivers about: (1) dementia, behavioral symptoms and resources (see Resource List); (2) the importance of early detection and physician notification; (3) patients' need for adequate stimulation and structured daily routines; and (3) taking care of themselves (Box 1). As behavioral risk factors include caregiver distress, patient pain, sleep disturbance, inadequate nutrition, infection or other acute medical illnesses,^{8,51,52} proactively evaluating for their presence and addressing them is equally important.

In Mr A's case, early detection of his nocturnal hallucinations and sleep disturbances by using a behavioral symptom checklist with the caregiver at each visit may have identified these behaviors when they first emerged so they could have been managed immediately. Providing Mr Z early on with targeted nonpharmacologic sleep hygiene strategies (eliminating caffeine by afternoon, establishing structured nighttime routines) may have prevented caregiver exhaustion. Also, early and on-going detection of Mr A's declining abilities and providing caregiver education about risks for Mr A staying home alone may have prevented his wandering and emergency department visit.

Describe Presenting Behaviors (Figure 1–Step 2)

Mr Z: 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 a more formal assessment to describe and differentiate symptoms. This involves interviewing patient and caregiver to characterize behavior(s) and the circumstances of occurrences. Differentiating behavioral symptoms is important. For example, agitation encompasses varied behaviors and may involve physical (hitting, pacing, biting, pushing), verbal (threats, screaming, attention-getting) and/or passive (withdrawal, handwringing, blank stare) attributes that should be delineated to derive specific treatment approaches.

The clinician needs to consider the patient's perspective and what happened according to him/her. However, with disease progression, the patient may be unable to accurately report or remember behaviors or will not fully comprehend risks for his/her safety; thus caregiver involvement becomes essential. (Box 2 provides questions for caregivers to help characterize behaviors.

When describing behaviors, two areas of immediate significance for triaging and developing a treatment plan are safety and level of caregiver distress.⁵² Box 3 lists common safety concerns contributing to or triggered by behavioral symptoms. Safety concerns will depend upon the patient's cognitive functioning and living situation: as patients become more impaired, they need more supervision to remain safe, as Mr A illustrates. Referral to an occupational therapist or other qualified professional for a comprehensive home safety evaluation would be appropriate.^{53,54}

Safety concerns for Mr A included being home alone while the caregiver worked, his inability to respond effectively to emergency situations, and lack of caregiver follow-

through with obtaining a safety alert necklace. While Mr A's complaint of night-time noises did not at first appear to endanger the patient or caregiver, Mr Z's lack of sleep put him at risk for indirect health concerns (e.g., sleep deprivation leading to poor health or accidents) and poor work performance. As safety became an increasing concern, Dr J spent more clinical time educating the caregiver as to Mr A's declining capabilities and increasing need for daily oversight, and identifying alternatives to him remaining at home alone.

Also of importance is determining the caregiver's burden level to evaluate the urgency of modifying behavior(s).⁵⁵ Caregivers may consider one behavior versus another as more distressing to them. In some cases, caregivers may experience a behavioral symptom "personally", feeling that the patient is "doing this on purpose to bother them." Box 4 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 anti-depressant medication.

Identify Underlying Causes (Figure 1–Step 3)

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 something that is making him delirious or a medication change?*

Step 3 involves identifying possible causes for identified behaviors. Potential causes may be patient-related, caregiver-related or environment-related (Box 5). As Dr J indicates, her immediate concern was whether patient-related factors (medical illnesses, pain, medications), were contributors, particularly important with acute or subacute behavioral onset. Dr J ruled out medical conditions (pain, infection, medications), determined that Mr A was not depressed, and discerned that hearing might be an issue as hearing loss is a potential risk factor for developing delusions or hallucinations in older adults.

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.*

The clinician should also observe the caregiver's coping and communication styles, closeness to patient, and availability of support (Box 5). Negative communications (yelling, harsh tone, criticizing) are associated with increased patient agitation; dysfunctional (e.g., problem will go away if ignored) versus problem-solving coping (e.g., proactive, task-focused) is associated with poorer patient outcomes; whereas a close relationship with the patient is associated with better patient outcomes.⁵⁶ Cultural expectations and values can also influence care decisions. In Mr A's case, most family members lived in Mexico. His cousin willingly assumed care responsibilities but had limited local support. As he needed to work, he was becoming distressed.

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

Mr A's story highlights how living situations impact nonpharmacologic treatment decisions. Financial constraints may compromise use of nonpharmacologic approaches or contribute to caregiver burden. As financial strain and caregiver burden are predictive of nursing home placement,⁵⁷ recognizing these and other contextual factors, as exemplified by Dr J, and working with families to address them, is part of a nonpharmacologic approach.

An under-examined contributor to behaviors is the home environment such as the presence of excessive stimulation (noise, number of people, clutter), under-stimulation (no objects to view or touch, poor lighting), inappropriate room temperature (too hot or cold), and way-

finding challenges (difficulties locating bathroom, bedroom, kitchen).⁵³ This can be gleaned through key informant interviews or direct observation through a home evaluation by occupational therapists or other qualified professionals.

Devise a Treatment Plan (Figure 1-Step 4)

Although antipsychotic use has declined, there is still over-reliance on these and other pharmacologic treatments, despite limited efficacy data and increased mortality and morbidity (e.g., falls) risks.^{40,58} Moreover, no pharmacologic solutions address potential underlying causes of behaviors or behaviors most distressful to families.³²

A treatment plan may include generalized and behavior-specific targeted approaches and if necessary, referrals to dementia specialists (geriatric psychiatrists, neurologists specializing in cognitive disorders, geriatricians; nurses, psychologists, social workers, occupational therapists, physical therapists).

Generalized nonpharmacologic approaches address behaviors by improving daily life overall. Evidence from randomized, controlled clinical trials supports use of structured activity, caregiver education and training, and adult day services with small to very large effect sizes reported.⁵⁹⁻⁶⁵

Activity

Mr A: *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.*

Physical exercise plus caregiver training in behavioral management techniques can reduce patient depression,⁶⁶ although unclear is the specific dose, intensity, and type of exercise that maximizes benefit. As formal exercise routines can be difficult to implement, simple activities such as taking routine daily walks with the caregiver can enhance feelings of well-being and sleep. Purposeful activities (social, cognitive, physical) with intrinsic interest or meaning to the patient and that are graded to their capabilities (e.g., executive function, motoric abilities) can reduce agitation and other behaviors families find disruptive.⁶⁷ 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. Purposeful and regular activities at home that tap into previous interests and procedural memory can prevent or reduce agitation and depression.^{67,68}

Caregiver Education and Training

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

A meta-analysis of 23 randomized clinical trials provides strong confirmation of the benefits of caregiver education and skills training interventions for reducing behavioral symptoms. Collectively, these trials involved 3,279 community-dwelling caregivers and patients. Significant treatment effects were demonstrated for reducing behavioral symptoms [effect size=0.34 (95% CI: 0.20 – 0.48, Z=4.87; p<0.01) and caregiver negative reactions [effect size=0.15 (95% CI: 0.04 – 0.26, Z=2.76; p=0.006).⁶⁵ Even small improvements can make a critical difference in helping patients to continue living at home with quality of life.

Effective interventions were wide-ranging and included caregiver education, skills training (problem solving, communication strategies), social support (linking caregivers to others), and/or environmental modifications (assistive device use, creating a quiet uncluttered

space). Interventions varied in dose, intensity, and delivery mode (telephone, mail, face-to-face, groups, computer technologies); however, the most effective were patient-and caregiver-centered such that information and support addressed the challenges families identified as troublesome. Addressing multiple areas of immediate need and providing problem-solving skills to prevent, manage, or minimize behavioral occurrences were common among effective interventions.⁶⁵ Although not all caregiver support programs (e.g., counseling) result in behavioral symptom reduction, benefits for caregivers overall are manifold and equally important and include enhanced skills and confidence, less distress with behaviors, and nursing home placement delay.⁶⁴

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.⁶⁹ Alternately, referral to local Alzheimer's Associations may be helpful. Some branches offer caregiver interventions and group support. Patients with safety issues or functional limitations can be referred for occupational therapy home evaluation and treatment which may be reimbursable and affords an opportunity for systematic caregiver education and instruction in behavioral management.⁷⁰

Adult Day Services

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.

A systematic review of studies on adult day services shows multiple benefits including reductions in behavioral symptoms and caregiver distress.^{71,72} However, level of exposure for symptom reduction is unclear and outcomes may be patient-specific.

Other Generalized Strategies—Music interventions ranging from recorded music or music activities in individual or group settings are promising.⁷³ Musical abilities appear preserved in some patients. A few randomized trials found reduced aggression, agitation and wandering while patients were engaged in music although more careful research is necessary.⁷³

Evidence for other nonpharmacologic approaches is inconclusive. A systematic review of 17 controlled studies testing cognitive training using compensatory (e.g., learning to organize or visualize information) or restorative (e.g., spaced retrieval requiring patients to recall information over progressively longer time frames) strategies found a medium effect size (0.47) in many areas of functioning, yet limited evidence for improving behaviors.⁷³ Recent evidence from a year-long intervention involving psychosocial support and cognitive exercises (compensatory strategies) benefited mood and cognition in individuals with mild cognitive impairment and moderate dementia suggesting this is a promising area of investigation.⁷⁴

There is inconsistent to no evidence supporting reminiscence therapy (discussion of past activities, events, 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.^{73,75} There are no quality studies for acupuncture. [See Appendices A and B]. Most studies are limited by small samples, lack of methodological rigor and precision in measuring behavioral symptoms, or exclusive focus on nursing home residents.

Generalized Strategies for Disease Stages—Most generalized strategies have been evaluated with patients at mild to moderate dementia yet may be effective in mild cognitive impairment. For example, caregiver education concerning functional consequences of memory loss, training patients in compensatory strategies (e.g., memory boards, calendars, external prompts), appear helpful although more randomized trials are needed.

There is insufficient research for nonpharmacologic strategies with severely impaired patients, although most community-based trials referenced above include some patients with MMSE scores <10. A meta-analysis of 21 nonpharmacologic therapies targeting patients in day hospitals or residential care facilities found limited, but moderate to high quality evidence for use of sensory-focused strategies such as calming music and aromas, reflexology (application of pressure to specific points on hands and feet), and other multi-sensory stimulation therapies.⁵¹ However, research is limited on the use of these techniques at home and whether caregivers can implement them effectively. (See Table 2 for generalized approaches for Mr. A).

Targeted Approaches

Mr Z: ... 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 (e.g., agitation when bathing). It typically involves problem-solving to identify precipitating and modifiable causes and consequences of the identified behavior, followed by efforts to modify these conditions (e.g., assuring bathroom is warm, water temperature not too hot). It relies on a key informant (family member) who works with the clinician to characterize the behavior and help identify modifiable factors and strategies (Figure 1, Steps 2 and 3).

A targeted approach would be useful for Mr A's sleep disturbance. It would first involve ruling out depression and other causes, examining the physical environment where he slept, and assessing his daily and bedtime routines (Figure 1, Steps 2 and 3). A home evaluation of sleeping quarters and nighttime routines by an occupational therapist or other qualified professional could provide important information for devising a treatment plan. Based on identifying potential contributing factors to the behavior, potential strategies might include eliminating caffeinated beverages and/or napping in the afternoon, implementing a structured daily routine of exercise and/or meaningful activity, implementing a structured nighttime routine possibly involving soft music, setting a tranquil tone, and removing stimulating environmental distractions (television). These approaches can be highly effective in managing sleep disturbances.

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 600 diverse families (Caucasian, African American and Hispanic) demonstrated that a targeted problem behavior approach combined with other caregiver support strategies (e.g., generalized approach) effectively reduced behavioral symptoms and associated caregiver distress.⁵⁹

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, whereas tracking devices and home alarms effectively detected wandering and locating lost patients

in uncontrolled, non-randomized studies.⁷³ For aggression, minimizing risk factors such as patient depression and pain, caregiver burden, and poor patient-caregiver relationship may be preventive.^{14,76} Alternately, educating caregivers in strategies to use when aggressive behaviors occur such as distracting the patient, backing away and leaving the room (if patient is safe) can be helpful. Studies of nursing home residents suggest that personalizing the bathing experience (e.,g, offering choice, creating a spa experience),⁷⁹ can minimize agitation and aggression; however, these strategies have not been tested in homes in randomized trials.

Determine Effectiveness of Nonpharmacologic Strategies (Figure 1-Step 5)

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 involves evaluating the effectiveness of the nonpharmacologic treatment for resolving behavioral symptoms. This includes determining whether the caregiver implemented the nonpharmacologic strategies, and if so, if they were implemented correctly, and then whether the behavior was resolved (eliminated, reduced severity and/or frequency or better management). For example, Mr Z did not followup with obtaining a safety alert bracelet for Mr A.

As shown, Dr J tried various strategies until resolution was obtained. If there are no behavioral improvements, it is important to determine if characteristics of the behavior or the patient's environment or health status have changed, or if the strategy itself is not effective. Specialist referral should also be considered at that point.

On-going Monitoring (Figure 1-Step 6)

As behavioral symptoms fluctuate and the patient's context change, Figure 1 and its steps reflect a repetitive cycle. Essential to using nonpharmacologic approaches is monitoring treatment plans. If resolution using strategies is not obtained, other treatment options such as referral to specialists should be considered.

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.⁷³ Increased agitation and physical aggression has also been reported for some sensory approaches (music therapy, massage/touch therapies, aromatherapy).^{73,78} As nonpharmacologic modalities involve manipulations of persons, behaviors, cognitions and environments, they represent active treatments necessitating careful monitoring of behavioral improvement or worsening, with particular attention to potential for heightened agitation.

Challenges

One challenge is that our framework may be labor intensive as it involves on-going evaluation, problem-solving, strategy modification, and access to dementia care specialists (geropsychiatrists, occupational therapists, nurses, social workers). Reimbursement and care systems do not adequately support their use. Busy clinicians may find it challenging to integrate the 6-steps over short patient visits. However, forming a dementia team with other health professionals is an effective strategy to address this potential challenge.⁷⁹ Another challenge is lack of guidelines for starting or stopping strategies. However, essential to using strategies is ongoing monitoring. Yet another challenge is that nonpharmacologic strategies may be effective for certain symptoms (repetitive questioning, agitation), but not others (hallucinations). Although guidelines for using nonpharmacologic strategies by disease stage and behavioral-type are still needed, this should not deter their use now. It is also unclear as to the best combination of strategies for optimizing treatment effects or how nonpharmacologic and pharmacologic approaches may augment each other.

There may be no single approach for addressing any one behavior; it may require a multi-component approach (generalized plus tailored). Our 6-step framework serves as a guide for clinicians to consider multiple approaches. Finally, detection, assessment and behavioral symptom management may be challenging to apply to patients with dementia who live alone and do not have family.

Conclusion

Behavioral symptoms are a major source of disability making their clinical management critical. Unfortunately, most patients treated in primary care do not receive thorough assessment, treatment and monitoring of behavioral symptoms.^{80,81} Mr. A experienced numerous behavioral symptoms including hearing voices at night which often trigger a physician's prescription for an anti-psychotic. However, as illustrated, a combination of nonpharmacologic strategies including an evaluation of Mr A's hearing and hearing aids effectively managed his sleep disturbance without drug use.

There is strong evidence for both generalized and targeted nonpharmacologic treatments. Essential to a nonpharmacological approach is educating caregivers in ways to effectively prevent and manage behavioral symptoms. As 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.

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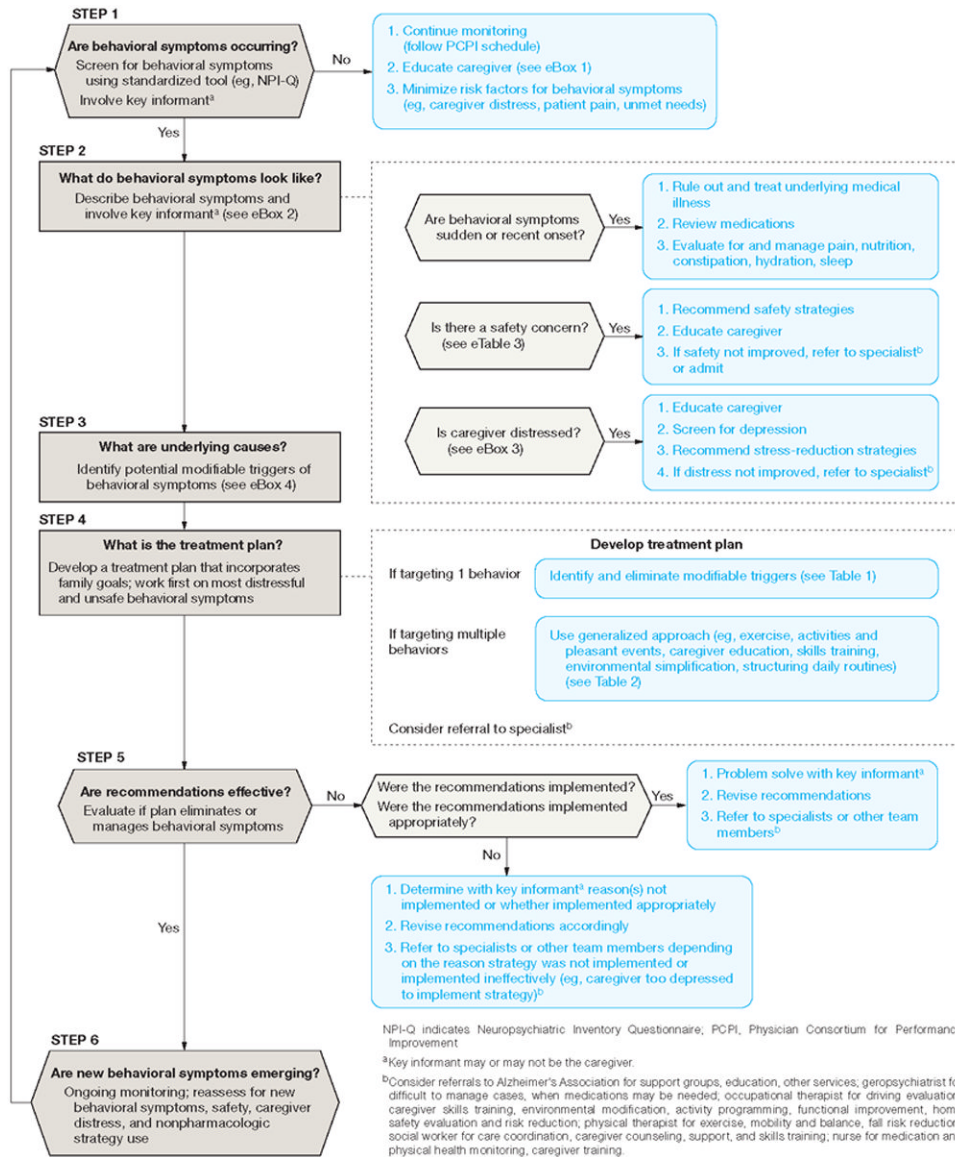


Figure 1. Screening, identifying, and Managing Behavioral Symptoms in Patients With Dementia

Table 1
Potential Nonpharmacologic Strategies to Manage Mr. A's Targeted Behaviors

Presenting Behavior	Select Nonpharmacologic Strategies
Behaviors at mild cognitive impairment stage	
Forgetful about medication taking	Evaluate capacity for taking medications independently Use assistive aid (calendar to remind time for medication; checklists, pill dispenser) Supervise medication-taking and do not keep medications accessible
General forgetfulness; disorientation to time	Use memory aids (calendars, white board with date) Simplify daily routines
Behaviors at moderate dementia stage	
Hearing voices or noises (especially at night)	Evaluate hearing and adjust amplification of hearing aids Evaluate quality and severity of auditory disturbances; if hallucinations judged to be present, evaluate whether they present an actual threat to safety or function in deciding whether or not to use antipsychotic treatment
Nighttime waking, turns on lights, wakes caregiver, feels insecure at night	Evaluate sleep routines Eliminate caffeinated beverages (starting in afternoon) Exercise and activity throughout the day Use nightlight Hire night time assistance to enable caregiver to sleep Evaluate environment for temperature, noise, light, shadows, or other possible disturbances Create a structured day and quiet bed time routine Increase physical activity and activity engagement during the day Limit Mr. A's daytime napping Address Mr. A's daytime loneliness and boredom which may contribute to nighttime insecurities
Repetitive questioning	Use calm, reassuring voice Use calm touch for reassurance Inform patient of events as they occur (versus indicating what will happen in near or far future) Structure daily routines Provide meaningful activities during the day to engage patient Use distraction
Leaves home and wanders outside	Alzheimer's Safe Return Program (ID bracelet), badge with name and address Notification of police and neighbors of Mr. A's condition Identify potential triggers for elopement and modify them
Unable to respond to emergency (difficulty calling for help)	Educate caregiver about need to supervise patient Inform neighbors, firemen and police of situation Develop emergency plan involving others if possible
Falls and poor balance	Fall alert system if patient is capable of remembering to push button

Presenting Behavior	Select Nonpharmacologic Strategies
	Consider referral to occupational therapy for home safety evaluation and removal of tripping hazards Minimizing alcohol intake Consider referral to physical therapy for simple balance exercise
Memory-related such as disorientation, confusion recognizing objects	Label needed objects Remove unnecessary objects for a task to reduce confusion Lay out one object at a time as needed Keep all objects for a task in a labeled container (e.g., Grooming)
Restless at night	Implement good sleep hygiene Provide physical activity routine during the day Provide calming activity as part of night time routine Use calming music Assess environment for level of comfort and possible disturbances (light from street, noises, temperature) Consider adult day services

Note: Bold refers to strategies discussed, considered or implemented by Mr. A’s physician and caregiver. Strategies listed 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 one strategy may not have been evaluated for effectiveness for use with all dementia patients with the same presenting behavior. Strategies listed above should only be considered once thorough assessment (description and decoding – Figure 1, steps 2 and 3) has been completed.

Table 2
General Nonpharmacologic Strategies for Managing Behavioral Symptoms

Domain	Key Strategies
Communication	<ul style="list-style-type: none"> Allow patient sufficient time to respond to a question Provide one to two step simple verbal commands Use calm, reassuring tone Offer simple choices (no more than 2 at a time) Avoid negative words and tone Use a light touch to reassure, calm, or redirect Identify self and others if patient does not remember names Help patient find words to express him/hers
Simplify environment	<ul style="list-style-type: none"> Remove clutter or unnecessary objects Use labeling or other visual cues Eliminate noise and distractions while you are communicating or when patient is engaging in an activity Use simple visual reminders (arrows pointing to bathroom)
Caregiver education and support	<ul style="list-style-type: none"> Understand that behaviors are not intentional Learn how to relax the rules (e.g., no right or wrong in performing activities/tasks as long as patient and caregiver is safe) With disease progression, patient may have difficulty initiating, sequencing, organizing and completing tasks without guidance and cueing Go along with patient's view of what is true and avoid arguing or trying to reason or convince Take care of self; find opportunities for respite; practice healthy behaviors and preventive doctor visits Identify and draw upon a support network
Simplify tasks	<ul style="list-style-type: none"> Break each task into very simple steps Use verbal or tactile prompt for each step Provide structured daily routines that are predictable
Activities	<ul style="list-style-type: none"> Introduce activities that tap into preserved capabilities and previous interests Introduce activities involving repetitive motion (washing windows, folding towels, putting coins in container) Set up of the activity and helping patient initiate may be necessary

Note: Domains and strategies listed 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 one strategy may not have been evaluated for effectiveness for use with all dementia patients with the same presenting behavior. Strategies listed above should only be considered once thorough assessment (description and decoding – Figure 1, steps 2 and 3) has been completed.