

Chapter 5

Behavioral Interventions for Those Living with Dementia



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Overview of Behaviors

In looking at behavioral interventions for people with major neurocognitive disorder, dementia, it is difficult to separate personal experience from published research. Despite limited evidence to support long-term behavior changes with the use of nonpharmacological interventions in dementia, evidence does support caregiver training for improving targeted behaviors. Person-centered care planning must be considered when choosing interventions. Special consideration will be given to techniques that promote activities of daily living participation to decrease caregiver burden. In addition, focusing on individual preference and understanding personal history are essential to the person-centered care model.

Alzheimer's disease and other dementias are growing by epidemic proportions in the United States. As of 2018, Alzheimer's was the sixth leading cause of death with over 15 million unpaid caregivers supporting this incurable disease [1]. One in three seniors will die with a dementia condition

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[1]. Despite being known for cognitive loss, dementia has significant behavioral challenges that increase as the disease progresses. Current research indicates 60–80% of people with dementia present with neuropsychiatric symptoms which are the largest burden on care providers [5]. During the course of the disease, aggression, depression, restlessness, and delusions are common [9, 13]. Neuropsychiatric symptoms (behaviors) are defined in many ways. The Neuropsychiatric Inventory (NPI) categorizes these behaviors as delusions, hallucinations, agitation, depression, anxiety, euphoria, apathy, disinhibition, motor disturbance, nighttime behaviors, and appetite changes [8]. Table 5.1 describes the NPI's definition of behavioral disturbances in behavioral terms for caregivers.

Many scales exist to stage dementia. The DSM-5 defines neurocognitive disorder as minor or major, with major neurocognitive disorder being synonymous with the term dementia. Functional loss in everyday activities defines the difference between diagnosing minor and major neurocognitive disorder [2]. National Institute on Aging task force recommendation also includes using loss of function to mark later stages of the disease [21]. Functional impairments include language loss, decreased occupational engagement, and observable loss of self-care function [21]. Apraxia, aphasia, and agnosia are all common in late stage dementia. Apraxia is defined as a motor planning deficit, often present after a CVA or damage to the frontal lobe. People with apraxia demonstrate difficulty carrying out procedural steps of a task without other motor or sensory deficits. Aphasia, due to damage in frontal or temporal lobe of the left hemisphere, refers to receptive or expressive language. Gnosia, object recognition, is a cortical visual skill. Agnosia refers to person with dementia's loss of object recognition. Because of severe functional and cognitive loss, engagement in meaningful activities and self-care becomes more difficult. However, caregiver support and environmental changes have shown to significantly reduce

TABLE 5.1 Neuropsychiatric Inventory definition of behaviors

Neuropsychiatric		
symptom	Defined by NPI	Frequent observation
Delusions	False beliefs	Scared of partner cheating Kids stealing money
Hallucinations	False visions	Seeing people or pets others cannot see
Agitation	Resistive to help	Uncooperative with self-care
Depression	Demonstrates sadness	Reports feeling sad; acts sad
Anxiety	Upset with separation; signs of nervousness	Unable to relax even during enjoyable activity
Euphoria	Too happy	Excessive silliness that is not congruent with context
Apathy	Less interested in normal activities	No enjoyment of activities that are meaningful
Disinhibition	Impulsive or inpatient	Says angry things; hurts people's feelings
Motor disturbance	Repetitive activities	Layers clothes, perseverates activities (does steps over and over)
Nighttime behaviors	Poor sleep pattern	Gets up early, wakes up early
Appetite	Weight gain or loss	Change in food preferences or patterns

Adapted from NPI scale [8]

behaviors and delay placement outside the home [29]. A review of nonpharmacological interventions indicates that responses to direct sensory, cognitive, and emotional supports all need additional evidence and have limited long-term effects on disease reduction of challenging behaviors [18, 24]. Evidence relating efficacy of nonpharmacological interventions to improve quality of life specifically in people with severe dementia is significantly limited [7]. Due to safety concerns and despite limited evidence, nonpharmacological interventions are recommended prior to using pharmacology to decrease neuropsychiatric symptoms [13]. A 2018 systematic review of nonpharmacological interventions found that functional-based interventions should be used as first-line management of behaviors [12]. Neuropsychiatric symptoms often lead to challenging behaviors. Without caregiver training, attempting interventions can lead to poor outcomes and decreased cost-effectiveness for people with dementia [23]. Cohen-Mansfield and colleagues demonstrated that many doctors and nurse practitioners need additional education and resources to appropriately recommend and explain non-pharmacological interventions [6]. Due to the frequent turnover in caregiving staff, education is often seen as an expensive option for interventions. However, in 2017 study, data suggest that caregiver participation in a behavioral interventions does not increase may actually decrease costs of care [22]. Evidence suggests the need for additional practical education by providing behavior-specific interventions to enhance the quality of life for people with moderate-severe dementia and their caregivers.

Interventions in Major Neurocognitive Disorder

Advanced, moderate-severe, dementia is defined by the loss of ability to engage in routine activities and decreased ability to complete self-care [18]. Specifically, advanced dementia is marked by loss of language, incontinence, poor sequenc-

ing activities of daily living, and disinhibited behavior [4]. However, homogeneous sample studies that relate only to major neurocognitive disorder are extremely limited. Traditionally, dementia studies include people with mild, moderate, and severe dementia which increases the heterogeneity of the sample [29]. In addition, because dementia is an umbrella term for many conditions, participants in each study may have a varying types of brain damage. Kverno et al.'s [18] systematic review of nonpharmacological interventions in dementia discovered that out of 215 dementia studies, less than 10% focused on advanced dementia.

As shown in Table 5.2, behavioral interventions are divided into emotion-oriented interventions, sensory-oriented interventions, and environmental adaptations. Due to severity of illness, cognitive-oriented strategies are not appropriate in major neurocognitive disorder [18]. The evidence base for sensory, emotional, and environmental interventions demonstrates a need for continued study and more high-level research studies in advanced dementia [18, 20, 24]. However, evidence does support that the presence of a trained caregiver providing individualized interventions does show an immediate reduction in symptoms. Short-term benefits provide relief for caregivers and provide the ability to connect with the patient in the moment. In a systematic review of nonpharmacological intervention, person-centered interventions showed significant reduction in difficult behaviors [24].

TABLE 5.2 Classification of behavioral interventions

Intervention category	Examples
Emotion	Validation of emotions; sharing memories
Cognitive	Cognitive-behavioral adaptations; reward system; time-outs
Sensory	Music, light, warm blankets, pet therapy
Environmental	Simplifying environment; Caregiver education

Emotional and Cognitive Interventions

Emotional interventions designed to decrease neuropsychiatric symptoms include validation, simulated presence, and reminiscence. Validation is speaking to the emotion, and not responding to the literal translation of communication. Use of validation of emotions in communication showed benefits in mild to moderate dementia but showed no benefits in severe dementia [18]. Simulated presence is the use of recorded voice or videos of a loved one to calm a person with dementia. Simulated presence has limited proven results including no significant difference in response between known and unknown presence and no lasting results in patients with severe dementia [18]. Reminiscence is commonly used to increase interaction and distract from negative feeling. It often involves helping to recall and share long-term memories. Livingston et al.'s [20] systematic review of nonpharmacological treatments reports elevation of mood during the reminiscence, but no long-term behavioral improvement. Because no evidence was found for cognitive interventions in severe dementia, these strategies will not be included in the proposed caregiver guide.

Sensory Interventions

Sensory interventions used to decrease neuropsychiatric symptoms included multisensory interventions, music, touch, movement, aromatherapy, and light. Kverno et al.'s [18] systematic review found four randomized controlled studies in severe dementia and sensory interventions. Evidence shows moderate results in reducing agitation and apathy when aromatherapy is utilized in a diffuser in common areas [18]. Hammar et al.'s [15] study of ten patients with dementia showed decreased negative behaviors, especially with care, when caregivers sang during activities of daily living. Such evidence appears to support that caregiver presence may be a strong factor in success of interventions. Multisensory interventions have been developed to meet hypothesized unmet

sensory needs in advanced dementia, especially in institutionalized environments. In a study of eight sessions using multi-sensory interventions, no increased benefit was found over structured activity [3]. Robichaud, Herbert, and Derosiers [27] found no improvement in behaviors of 40 people with dementia when sensory integration treatments were provided. Music and touch demonstrate decreased difficult behaviors during intervention but with no long-term effects [20, 26]. However, all these studies focused on long-term effects, not immediate reduction in behaviors. Because dementia is a progressive illness, long-term decrease in behavioral symptoms based on an isolated intervention is an impossible goal. However, short-term effects can be replicated when a caregiver is educated on appropriate interventions. Person-centered techniques are more efficacious than isolated interventions. For example, exercise and movement have proven benefit. Evidence supports improved strength and mobility, but not a long-term decrease in wandering or difficult behaviors [24]. However, in a study of 65 nursing home patients with severe dementia, Tappen, Roach, Applegate, and Stowell [30] found a significant decrease in agitation when walking and social conversation were combined. It was also found that 90% of agitated patients were able to complete a walking program when engaged in conversation. Evidence supports individualized interventions and combined use of multiple therapies when working with people with advanced dementia. Table 5.3 details common sensory interventions for behavioral challenges seen in people with major neurocognitive disorder.

Environmental Adaptions

Environmental interventions designed to decrease neuropsychiatric symptoms include modifying physical space, caregiver training, and adjusting activity demand. In 2011, Bédard, Landreville, Voyer, Verreault, and Vézina studied the effectiveness of addressing basic needs to decrease verbal agita-

TABLE 5.3 Sensory interventions

Intervention	Condition
Weighted item (vest, blanket)	Anxiety and apathy
Exercise	Agitation/aggression, depression, restlessness, and anxiety
Quiet space, low stim room	Aggression and anxiety
Baby doll, stuffed animal	Depression, anxiety, motor restlessness
Human touch – caregiver hand holding, massage, personal care (nails, lotion)	Depression, apathy, anxiety
Natural light and outdoor activity	Sleep changes, aggression, anxiety, and depression

tion and found a 50% reduction in verbal aggression when social and physical needs of the patient were addressed. Social and physical needs included comfort and interactions with other people. Meeting the needs of patients with advanced dementia can be difficult due to limited ability to identify and communicate needs. Patients with advanced dementia are reliant on their caregivers to assess basic needs, and therefore results of interventions vary based on accuracy of assessment [28]. Visual changes to space included use of mirrors, sign posting, and using visually complex environments. All had limited long-term reduction in agitation and restlessness [20]. Environmental adaptations need to take into consideration patients' basic need for comfort, and individualized approaches show modest efficacy with advanced dementia [26]. Such studies support that it may be the presence of the caregiver and focused interventions that truly reduce behavioral disturbance in dementia. For example, Doody et al. [10] report grading tasks, toileting schedules, and cues to complete self-care as a best practice approach for dementia, all of which are individualized treatment interventions. Kverno et al. [18] concluded that the most effective recommendations

TABLE 5.4 Environmental interventions [5, 13]

Intervention	Condition
Circular pathways	Anxiety, restlessness, and agitation
Pained walls/hidden exits	Agitation, restlessness, and anxiety
Caregiver training	Aggression and anxiety
Sleep hygiene (daily exercise, night routine)	Depression, agitation, anxiety, restlessness
Meaningful activities graded to abilities	Sundowning, aggression, anxiety, and depression, apathy and anxiety

were individualized schedules that assist with overarousal and under arousal states and environmental adaptations. Multisensory therapies, social contact, and environmental adaptations had limited effect, but they were limited in consistency of duration and intensity of intervention [24]. Spijker et al. [29] recommend consistent caregiver intervention with high ability and intensity to delay institutionalism. Caregiver training is proven to be the most recommended approach to provide care for people with dementia [7, 18, 24].

In summary, although nonpharmacological interventions in advanced dementia have limited data to support long-term effects of interventions, thoughtful and educated caregivers can provide individualized care plans that can reduce behavior disturbance and increase quality of life [16, 21]. The focused attention of a consistent caregiver may be the best intervention. Providing a caregiver education and meaningful activities is included in the category of environmental interventions. The broad scope of environmental interventions is seen in Table 5.4.

Pain and Quality of Life in Advanced Dementia

Pain is underrecognized and undertreated in dementia [17]. Pieper et al. [25] report that 50% of all nursing home residents with dementia have pain and 80% have behaviors that

are difficult for a caregiver to manage. To effectively treat pain, nonverbal signs of pain must be recognized and objectively assessed by a caregiver. Standardized objective measures such as the PAINAD are recommended to decrease pain [25]. Training caregivers in the assessment of nonverbal signs of pain is essential to quality of life of a person with dementia and the successful use of interventions to decrease neuropsychiatric symptoms. In a study of 352 nursing home residents with moderate to severe dementia, assessment and systematic treatment of pain decreased agitation by 20% [16]. Reliable observations of pain behavior require time and consistent report [28]. The caregiver guide will outline strategies to recognize and objectively measure pain.

As the disease progresses, quality of life is a significant issue in advanced dementia. Patients eligible for hospice continue to exhibit pain-related behavior and neuropsychiatric symptoms. Due to the severity of behaviors, many patients do not receive quality end-of-life care. In a study of 123 hospice eligible patients with advanced dementia, over 80% demonstrated significant behavioral challenges including sleep disturbance and aggression, yet few had nonpharmacological interventions provided [19]. Because nonpharmacological interventions have limited long-term effects without consistent approach, in-home caregiver training with tailored activity modification showed to be the most effective intervention for increasing quality of life in people with dementia [7]. The need for consistent caregiving to assess pain and increase quality of life supports the need for a specific caregiver guide for moderate to severe dementia. Pain must be considered when assessing a person with dementia who is exhibiting behavioral challenges. As seen in Table 5.5, nonpharmacological treatments for pain can vary from positioning to gentle massage.

In choosing a behavioral intervention, Fig. 5.1, person-centered plan of care, describes an evolving process. For patient-centered care, interventions of all types need to be based on an individualized assessment of strengths, unmet needs, and previous life preferences. A thorough review of

TABLE 5.5 Nonpharmacological interventions for pain

Intervention	Examples
Positioning	Bed and wheelchair Evaluate ability to self-propel Evaluate cushion Evaluate height of backrest Ergonomic evaluation by occupational therapy
Touch and massage	Evaluate and treat high or low muscle tone Regular one-step exercise Stretch Heat
Caregiver training	Pain assessment (verbal and nonverbal)
Sleep hygiene (daily exercise, night routine)	Positioning, daily exercise, nighttime routine, natural light during the day, nutrition, and toileting before bed
Meaningful activities graded to abilities	Activities that engage a person cognitively, emotionally, and physically

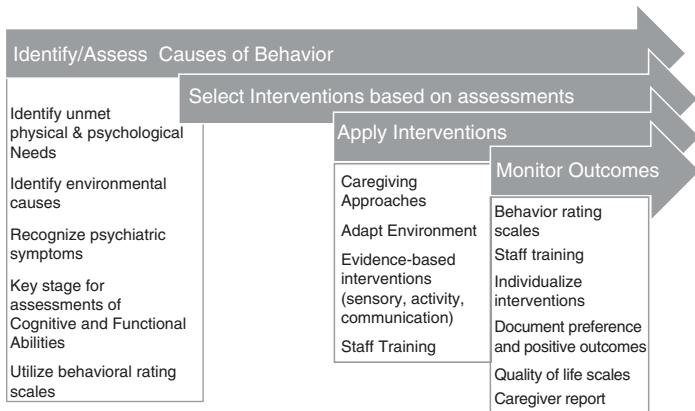


FIGURE 5.1 Person-centered plan of care. (Also featured in Activities of Daily Living Chapter. Created for this text by Foidel, 2018) [14]

meaningful lifetime occupations and sources of joy needs to be utilized. In addition, individual sensory preferences need to be honored and recorded in a care plan. For example, people have individual reactions to music, massage, and animal-assisted therapy. Information should be gathered through a functional assessment, sensory exploration, and interview of family and previous caregivers. Modifying a person's environment to allow for continued habits and routines can maximize independence and fully utilize strengths of a person with dementia.

Case Study: Gregory

Gregory is a 65-year-old man with advanced Alzheimer's dementia. He has a history of working as a mechanic in a rural area and was a boxer in his youth. He is a life-long bachelor. He is extremely combative with showers and often refuses to change his clothes. He crosses his arms and stands in the entryway – following guests and going toward doors in his memory care unit.

Evaluation of Sensory Preferences

- Enjoys “hard work” stacking, moving objects, and repetitive exercise
- Irritated with loud noises (loud visitors, shift change)
- Enjoys country music
- Low back pain noted; does not like to sit for greater than 10 minutes
- Wakes up very early (3 am) and likes to go to bed early – sleeps well when busy during the day

Evaluation of Abilities and Challenges [11]

- Can complete 1–2 step tasks
- Able to complete familiar ADLs when cued to initiate
- Limited language skills; aphasia makes speech vague
- Independently ambulatory
- Strength and ROM within normal limits

Intervention Ideas Based on Personal Preferences

- Allow Gregory to be awake early and work on a 1–2-step exercise such as stacking boxes, mopping floor, or moving baskets full of laundry (hard work early in the am mimics life as a farmer).
- Shower in the late afternoon. Place all supplies needed in bathroom and start warm shower. Cue to initiate and then just observe for safety. Recommend female caregivers (habits and routines).
- Regular exercise and ability to walk during the day (maintain sleep at night and help with pain).
- Consider headphones with country music to decrease irritation with noises happening in care facility.
- Keep routine simple. Allow patient safe choices. Avoid shift change.

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