Behavioral and psychological signs and symptoms of dementia: a practicing psychiatrist's viewpoint

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pproximately 10% of persons who reach the age of 65 will develop Alzheimer's disease (AD) or another type of dementia. AD and other dementias usually present with two syndromes, a cognitive syndrome and a behavioral syndrome, which overlap (in most patients) during the course of the disease. The cognitive syndrome is characterized by deficits in memory, language, visual constructional abilities, and other areas of intellectual functioning. The behavioral syndrome is characterized by symptoms of psychosis, aggression, depression, anxiety, agitation, and other common, but less well-defined, behavioral symptoms.

Alzheimer's disease typically presents with two often overlapping syndromes, one cognitive, the other behavioral. The behavioral syndrome is characterized by psychosis, aggression, depression, anxiety, agitation, and other common if less well-defined symptoms subsumed under the umbrella entity "behavioral and psychological symptoms of dementia" (BPSD), itself divided into a number of subsyndromes: psychosis, circadian rhythm (sleepwake) disturbance, depression, anxiety, and agitation. It is BPSD with its impact on care providers that ultimately precipitates the chain of events resulting in long-term institutional care. The treatment challenge involves eliminating unmet medical needs (undiagnosed hip fracture and asymptomatic urinary tract infection or pneumonia). Pharmacologic intervention relies on risperidone and, increasingly, cholinesterase inhibitors for the control of psychosis (but with response rates of only 65% at tolerable doses), olanzapine and risperidone for anxiety, and carbamazepine and valproic acid for agitation. However, evidence increasingly favors nonpharmacologic interventions, to the extent that these should now be considered as the foundation of BPSD treatment. Problem behaviors are viewed as meaningful responses to unmet needs in the therapeutic milieu. Because the progression and impact of BPSD varies between patients, interventions must be explored, designed, implemented, and assessed on an individual basis. They include: family support and education, psychotherapy, reality orientation, validation therapy, reminiscence and life review, behavioral interventions, therapeutic activities and creative arts therapies, environmental considerations (including restraint-free facilities), behavioral intensive care units, and workplace design and practices that aid the ongoing management of professional caregiver stress.

Keywords: dementia; Alzheimer's disease; behavioral and psychological symptoms of dementia; pharmacological treatment; nonpharmacological treatment

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Selected abbreviations and acronyms

AD	Alzheimer's disease
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BEHAVE-AD Behavioral Pathology in Alzheimer's Disease

Rating Scale

BICU behavioral intensive care unit BPRS Brief Psychiatric Rating Scale

BPSD behavioral and psychological symptoms of

dementia

CBT cognitive-behavioral therapy

CMAI Cohen-Mansfield Agitation Inventory
DAT depression of the Alzheimer's type
EPS extrapyramidal symptoms

GAD generalized anxiety disorder

GBS Gottfries-Bräne-Steen dementia rating scale

NPI Neuropsychiatric Inventory
PHF paired helical filaments
RO reality orientation
SCU special care unit
TD tardive dyskinesia

Even though both syndromes have devastating consequences for patients and their care providers, it is the presence of behavioral symptoms and their impact on care providers that ultimately precipitate the chain of events that results in the demented patient's placement in a long-term care institution. This paper will focus on the behavioral and psychological symptoms of dementia. This focus was chosen because of the considerable treatment challenge these symptoms present to clinicians and the burden they impose on patients, care providers, and society.

Historical perspective

Although physicians have been aware of the presence of behavioral symptoms in dementia since AD was first described, a definition of these symptoms was not attempted until 1986. In 1986, the syndrome defined was agitation, ie, "inappropriate verbal and motor behaviors that are not related to unmet needs or confusion per se." Soon clinicians and researchers realized that the problem was more complex than the aforementioned and that patients presented not only

symptoms of agitation, but also symptoms of aggression, psychosis, alteration in circadian rhythm, depression, and more.¹⁰ In 1996, the International Psychogeriatric Association (IPA) called a consensus conference to examine the available knowledge on noncognitive symptoms of dementia. The goal of the conference was to achieve consensus on the use of more appropriate descriptive terms that would facilitate communication among researchers and therefore foster further development of the field. The experts in attendance agreed on an umbrella term that would include all behavioral symptoms observed in the dementia. The term was "Behavioral and Psychological Symptoms of Dementia" (BPSD),11 defined as "signs and symptoms of disturbed perception, thought content, mood or behavior that frequently occur in patients with dementia."12 As new treatment options and scientific information emerged, another meeting was called by the IPA. This meeting evaluated the new data and concluded that a number of subsyndromes could be identified within the BPSD umbrella. These syndromes were psychosis, circadian rhythm (sleepwake) disturbance, depression, anxiety, agitation, and other less well-defined syndromes. The following is a brief summary of the current knowledge on BPSD with suggestions as to how this information can be applied to patient care.

Etiology

The etiology of BPSD is unknown. However, most experts probably agree that the etiology of BPSD is related to specific neuropathological brain lesions, ¹³ psychological and environmental factors, or a combination of both. ¹⁴ The specific localization of these lesions in the brain appears to be syndrome-dependent.

Neuropathological factors

Psychosis

As discussed previously, AD and other dementias are brain disorders presenting with a broad range of neuropathological lesions. When evaluating the etiology of psychosis in BPSD in AD, for example, researchers should not only establish the presence of neuropathological findings that explain the symptoms, but should also evaluate whether these findings differ between AD

patients with and without psychosis and nondemented psychotic patients. Fortunately, in recent years, a number of investigators have reported neuropathological findings that clearly differentiate the psychotic AD population from both schizophrenic and nonpsychotic AD patients. Specifically, AD patients with psychosis have increased neurodegenerative changes in the cerebral cortex, increased subcortical norepinephrine, reduced cortical and subcortical serotonin, and abnormal levels of paired helical filaments (PHF)–tau protein in entorhinal and temporal cortices.¹⁵

Circadian rhythm (sleep-wake) disturbance

It has been suggested that degeneration of the hypothalamic suprachiasmatic nucleus (SCN), the "biological clock" of the brain that imposes 24-hour rhythms in physiology and behavior, plays a key role in disturbed sleep-wake patterns.¹⁶ Degeneration of suprachiasmatic vasopressin cells has been demonstrated in postmortem studies on brain tissue of AD patients.¹⁷

Depression

Major depression in dementia of the Alzheimer's type (DAT) patients has been associated with increased degeneration of brainstem aminergic nuclei, particularly the locus ceruleus, and relative preservation of the cholinergic nucleus basalis of Meynert. Associated increases in the number of senile plaques or neurofibrillary tangles in the neocortex or allocortex have not been found. In addition, modest decreases in serotonin and 5-hydroxyindoleacetic acid (5-HIAA) levels have been found in AD patients.

Anxiety, agitation, and other BPSD syndromes

To the best of our knowledge, no specific relationship has been established between anxiety, agitation, and other BPSD syndromes and specific neuropathological findings in AD or other dementias. AD and other dementias, however, affect large areas of brain tissue and cause deficits in a broad range of neurochemical systems including gamma-aminobutyric acid (GABA), dopamine, substance P, and others.¹⁹ It is possible that future research will reveal relationships between those deficits and specific BPSD syndromes.

Psychological and environmental factors

To date, no clear relationships between most BPSD syndromes and specific psychological and environmental factors have been established.20 However, Cohen-Mansfield et al⁸ have studied relationships between patient needs, the environment, and agitation. Although a complete review of the literature is beyond the scope of this article a number of issues clearly emerge. The presence of unmet medical needs is an important contributor to all BPSD syndromes. For example, in an extensive nursing home study, Cohen-Mansfield and collaborators found that a large number of patients with verbal aggression had undiagnosed hip fractures.9 Furthermore, an evaluation of the correlation between behaviors such as verbal aggression and environmental factors shows that the quality of the patient's social environment is inversely proportional to the presence of verbal aggression. This suggests that an improvement in social interactions can have a therapeutic effect on verbal aggression. Indeed, a study by the same group of researchers shows intervention based on increasing social interaction to be better than a control intervention in the treatment of verbal aggression.8 Based on the aforementioned example, we believe that behavioral and environmental interventions should play a key role in the management of BPSD, thereby challenging clinicians and researchers to develop new and creative interventions.21

Conclusion

Although the etiology of BPSD remains unknown, available evidence suggests that a combination of behavior-specific biological and environmental factors may be partially responsible for the onset of BPSD.

Diagnosis

The diagnosis of BPSD is based on direct clinical history, direct observation, psychiatric and physical examinations, and reports by care providers. In addition, laboratory tests are used to evaluate the presence of medical conditions that can trigger or exacerbate the clinical presentation of BPSD.

The clinical characteristics of BPSD are syndrome-specific. The following is a brief description of some of the most commonly observed syndromes.

Psychosis

The symptoms of psychosis are defined by the presence of hallucinations and delusions lasting for one or more months. The onset of psychotic symptoms must occur after the onset of the dementia in order to fit this diagnosis. The main differential diagnosis is with late-onset schizophrenia; however, symptom presentation of BPSD psychosis is substantially different from schizophrenia. Symptoms such as misidentification of caregivers and visual hallucinations are common in BPSD psychosis and are rare in patients with schizophrenia. In contrast, patients with schizophrenia usually present Schneiderian first-rank symptoms, bizarre complex delusions, and active suicidal ideation. These symptoms are rarely observed in BPSD psychosis. Disease progression is also reported to be substantially different in BPSD psychosis. Psychosis in schizophrenia rarely shows remission, and the need for antipsychotic treatment is prolonged; psychosis in BPSD has a shorter duration and therefore requires shorter periods of treatment.

Circadian rhythm (sleep-wake) disturbance in dementia

Circadian rhythm disturbances among BPSD patients, termed sleep-wake rhythm disturbances for the purposed of this paper, make caregiving extremely difficult and are among the most important reasons for institutionalization. The prevalence of sleep abnormalities in demented populations may range from 20%-40%.^{22,23} Circadian rhythms are important regulators of sleep in humans. Sleep disturbances in patients with BPSD have been strongly associated with other BPSD symptoms such as wandering, daytime agitation, and the commonly described syndrome of increased agitation in the late afternoon known as "sundowning."24 Sleepwake cycles among patients with BPSD have been shown to degenerate and be replaced by arrhythmic polyphasic patterns of sleep.²⁵ Additionally, nocturnal sleep has been shown to be fragmented and associated with a tenfold increase in daytime sleep.26 The main differential diagnosis is with other sleep disturbances such as sleep apnea. Furthermore, the presence of BPSD sleep disturbances can coexist with other sleep problems, adding additional challenge to an already complicated diagnosis.

Depression

To our knowledge, no specific definition for BPSD depression is available. It is therefore recommended that the clinician use available definitions of depression such as those used in the *Diagnostic and Statistical Manual of Mental Disorders*, 4th edition (*DSM-IV*) published by the American Psychiatric Association. In addition, however, we recommend that some of the diagnostic considerations described herein be followed.

Depressive symptoms in demented patients often fluctuate and are particularly difficult to identify in patients with advanced dementia because of language impairment. Behavioral manifestations of depression (psychomotor slowing, emotional lability, crying spells, insomnia, weight loss, alexithymia, and nihilism) can occur in demented patients without depression.²⁷ Depressed patients with BPSD exhibit more self-pity, rejection sensitivity, anhedonia, and fewer neurovegetative signs than depressed older patients without dementia.²⁸ Research-based depression rating scales for demented patients have been developed to help discriminate between depressed and nondepressed demented patients, ^{29,30} and, while useful in research settings, widespread clinical application has yet to be adopted.

The natural history of major depressive disorder in BPSD patients is somewhat unclear. Most evidence suggests that major depression tends to emerge during the mild-to-moderate stage of cognitive impairment. Some studies suggest that the emergence of major depression in AD is associated with an increased mortality rate, but no acceleration of cognitive decline.³¹

Anxiety, agitation, and other BPSD syndromes

The presence of symptoms of anxiety in demented patients has high-phase validity among clinicians. Indeed, all currently available scales for BPSD include an anxiety item. The Behavioral Pathology in Alzheimer's Disease Rating Scale (BEHAVE-AD), for example, includes four anxiety-related items: anxiety regarding upcoming events, other anxieties, fear of being alone, and other phobias. Although the Cohen-Mansfield Agitation Inventory (CMAI) does not specifically address anxiety symptoms, it presents two categories that describe symptoms of anxiety. The categories are nonaggressive physical behavior and nonaggressive verbal behavior. The symptoms are pacing and aimless wan-

dering, constant request for attention, repetitive questions, trying to get to different places, complaining, and general restlessness. Finally, anxiety is one of the ten items evaluated for frequency and severity in the Neuropsychiatric Inventory (NPI).

It is, however, surprising that, despite leading investigators' acknowledgment of the presence of anxiety symptoms in dementia, no widely accepted qualitative definition is available for generalized anxiety disorder (GAD), the most common anxiety disorder in dementia. In the absence of other options, it is of interest to observe that Chemerinski and associates, using *DSM-III-R* GAD criteria managed to identify a distinct group of demented anxious patients.³²

To date, there is no universally accepted definition of agitation in BPSD. In the absence of such a definition, we propose using the clinical approach advocated by Cohen-Mansfield and collaborators. They view agitation as a group of inappropriate verbal and motor behaviors that are unrelated to the presence of unmet needs or confusion per se.⁸

Pharmacological treatment

As in previous sections the treatment of BPSD will be reviewed syndrome by syndrome. Because to our knowledge no specific syndromal approach is available for behavioral treatments, those will be jointly reviewed.

Psychosis and aggression

In 1998, little information was available on the treatment of psychosis and aggression in AD. An attempt to bridge this gap in knowledge was made using an expert consensus approach (A Special Report April 1998).33 The resulting report, which included survey results from approximately 80 experts, concluded that risperidone was the first-line treatment for psychosis in AD, followed by conventional antipsychotics. Extrapyramidal symptom (EPS) reactions and the long-term risk of tardive dyskinesia (TD) are potential concerns with conventional antipsychotics, especially at higher doses. Indeed, the rate of extrapyramidal side effects is reported to be as high as 20% in this population.³⁴ Further, the annual incidence of TD with conventional antipsychotic therapy is reported to be 25% in this population.³⁵ If patients are unresponsive to first-line therapy, the report recommended switching to another atypical antipsychotic, high-potency neuroleptic, or adding divalproex or trazodone. With regard to aggression, there was no majority agreement on first-line treatment; however, valproex was cited as the most popular of the treatment options. Divalproex was also suggested to be useful as an adjunct to antipsychotics in psychotic patients who continue to be severely aggressive (Expert Consensus Guideline Series, 1998).33 It is important to note this report was based on a survey completed in the two previous years, at which time the use of donepezil was limited (donepezil was launched in 1996). The major weakness in this information is in its source. Recommendations were based on a survey of experts rather than scientifically collected data.

In recent years, scientifically collected data from large multicenter trials began to emerge for the treatment of BPSD, especially psychosis. The first multicenter, randomized, double-blind, placebo-controlled trial of BPSD psychosis was recently published.³⁶ The study evaluated the effects of risperidone versus placebo in 612 demented patients. The study revealed risperidone to be significantly better than placebo in improving symptoms of psychosis and aggressive behavior when used in 1-mg and 2-mg doses.³⁶ A similar randomized trial37 of risperidone, placebo, and haloperidol for BPSD demonstrated conventional neuroleptics to be modestly efficacious for treating aggression in demented patients, while risperidone was associated with a greater reduction in both the severity and frequency of aggression than was either placebo or haloperidol. The antipsychotic drug olanzapine was also recently utilized in a randomized, double-blind, placebocontrolled study with AD. This study included 206 patients. This study found olanzapine 5 mg and 10 mg to be superior to placebo in the treatment of both psychosis and aggression in BPSD patients.38

Until recently, cholinesterase inhibitors were untested in treating BPSD symptoms such as agitation, delusions, and hallucinations. In a previous study, it was observed that patients given tacrine at 120 mg a day or higher were less likely to have entered a nursing home than patients on lower doses.³⁹ It was hypothesized that this decline was in part due to a decrease in the onset of noncognitive symptoms in those patients. Furthermore, in a study evaluating the effectiveness of physostigmine slow release (SR), Thal et al⁴⁰ reported a decrease in the onset of psychosis and aggression as well as other psy-

chiatric pathology in the physostigmine SR–treated groups. In addition, recent data on the cholinesterase inhibitor donepezil indicate that this compound can also improve behavioral symptoms commonly associated with psychosis in AD, such as hallucination, apathy, and aberrant motor behavior.⁴¹ Furthermore, another large multicenter trial using donepezil for AD treatment of nursing home (NH) populations revealed a statistically significant (*P*<0.05) difference (in favor of donepezil) in the individual agitation/aggression response of the NPI/NH assessment tool.⁴¹ Similar findings with rivastigmine and galantamine (both cholinesterase inhibitors) have recently been revealed.⁴²

The common limitation of all these studies is that 65% or fewer of the patients were considered responders either for psychosis or aggression at doses with a benign side-effect profile.^{36,43} Recently, researchers have speculated on the possible benefits of combining more than one treatment approach,³⁷ and future research will probably guide us on the use of these types of treatments.

Circadian rhythm (sleep-wake) disturbance in BPSD

Standard pharmacological treatment with benzodiazepine and antipsychotic medications has limited or even adverse effects in demented elderly people, including excessive sedation, confusion, impaired cognition, and personality changes.⁴⁴ Nonpharmacological treatments such as bright light therapy have been studied with varying results.⁴⁵⁻⁴⁸

Anxiety, agitation, and other BPSD syndromes

Only one report of a multicenter pharmacological clinical trial specifically addressing the response of anxiety symptoms in AD patients to treatment is available. The study presented by Street and associates (1999), reports on the response of anxiety symptoms in AD to olanzapine. In this study of 206 subjects treated in double-blind fashion with either placebo or olanzapine 5 mg, 10 mg, or 15 mg, the authors report a statistically significant reduction in the anxiety symptoms of the NPI in demented patients treated in the 5-mg group. Furthermore, a statistically significant symptom reduction over placebo was observed using the anxiety/depression items of the Brief Psychiatric Rating Scale (BPRS) (somatic concerns, anxiety, guilt feelings, and depressive mood) in the 5-mg and 10-mg olanzapine treatment groups.

It is of interest to observe the response of anxiety symptoms in another study evaluating treatment response of demented patients with BPSD.36 In this study, the investigators evaluated 612 demented patients presenting with psychosis, aggression, and a variety of other symptoms of BPSD. Patients were treated with risperidone 0.5 mg, 1 mg, 2 mg, or placebo. Although patients did not show response in the anxiety items of the BEHAVE-AD, they did show statistically significant improvement over placebo in the 1-mg and 2-mg patient groups on both anxiety-related items (see above) in the CMAI. Finally, Gottfries and associates (1992) evaluated the response to citalogram given at doses of 10 to 30 mg a day in 98 patients suffering from dementia and depression (see reference 18). They reported statistically significant differences with placebo in the anxiety items in demented patients as measured by the anxiety items of the Gottfries-Brane-Steen global dementia rating Scale (GBS). These changes are reported to occur at 4 weeks. To date, no report has addressed the issue of agitation in demented patients per se, although all previously reported studies find improvement in agitation as measured by the different rating scales. One recent report suggests that mood stabilizers can be of value in the management of agitation per se in the dementia population. The following is a brief review of the available literature on this subject.

Carbamazepine has been considered as a possible treatment for agitation in demented patients based on reports that it reduces impulsive behavior in other disorders.⁴⁹ Following initial reports, there have been four case reports44,50-52 three open-label studies,53-55 and two double-blind, placebo-controlled, crossover studies,56,57 all of which reported moderate improvement in a wide range of agitated behaviors. One of the most recent studies was conducted by Tariot and colleagues.⁵⁷ Using a nonrandomized, placebo-controlled, crossover design in 25 agitated patients, carbamazepine and placebo were administered during two 5-week periods, separated by a 2-week washout period. The carbamazepine dose was determined by a nonblinded physician (modal dose was 300 mg/day). This study included 25 subjects, and outcome measures showed significant decrease in overall agitation as determined by the BPRS (P=0.03) as well as in measures of global improvement (P=0.001). The authors concluded that carbamazepine could be a useful tool for the treatment of agitation in this patient population.

Valproic acid could also be useful in these patients, as described in the literature, ^{58,59} although large-scale double-blind studies are lacking. Side effects from mood stabilizers, such as sedation, confusion, and ataxia, should be clinically monitored. Routine laboratory tests should be performed during treatment with carbamazepine (eg, blood cell count for bone marrow suppression, electrolytes for hyponatremia, drug levels for toxicity) and valproic acid (eg, liver function tests for hepatotoxicity, drug levels for toxicity) in demented patients with agitation.

The use of lithium carbonate in the elderly is limited due to the risks of inducing delirium, ⁶⁰ particularly in the medically compromised patient. Schneider et al ⁶¹ found that lithium carbonate was effective only in one in six patients with AD and aggressive behavior. The literature suggests ^{62,63} that lithium can be considered in cases where aggressive behavior is related to mood instability.

Nonpharmacological interventions

Historically, older adults have not been considered good candidates for nonpharmacological, psychotherapeutic interventions.⁶⁴ However, an increasing number of researchers have studied the psychosocial issues confronting aging adults, and their response to individual and group therapies.⁶⁵

Literature reviews relating to specific psychotherapeutic interventions with elderly patients are available and include the behavioral assessment and treatment of anxiety, reduction in insomnia, behavioral management of dementia, the use of reminiscence therapy, and group family caregiver interventions.⁶⁶⁻⁶⁹

A detailed literature review of BPSD patients demonstrated that most studies are of a pharmacological type and that there are few systematic studies of behavioral or environmental interventions. The existing studies rarely specify a syndrome. These studies often relate to specific behaviors, such as wandering, or to treatments recommended for a given stage of dementia. For this reason, in this section we will depart from the previously used syndromal model and review nonpharmacological interventions as a group.

Nonpharmacological interventions should be considered the foundation of treating behavioral symptoms in persons with BPSD. Because the progression and impact of BPSD vary from person to person, it is critical that interventions be explored, designed, implemented, and assessed on an individual basis. It is important also to

consider that a number of interventions can be utilized with one individual and that many of the interventions are beneficial to family and professional caregivers, as well as the person with BPSD (for example, music therapy, relaxation techniques, etc). It should be noted that these interventions may also be very beneficial to persons who have dementia and do not exhibit BPSD symptoms. In discussing nonpharmacological approaches, particular emphasis will be placed on family support and education, behavioral interventions, environmental considerations, special care units, and professional caregiver stress.

Family support and education

Family caregivers of persons with dementia have been the focus of extensive research. Studies have consistently demonstrated that caregiving is stressful and can result in increased psychological and physical distress.^{72,73} Family caregivers often prefer avoiding or delaying the placement of elderly members in a long-term care facility, and spouses of caregivers are even more reluctant to do so than other relatives.74 Literature reviews by Zarit and Teri have summarized the research on various psychoeducational, psychotherapeutic, and self-help interventions that have been used with persons caring for an older adult.75 There is evidence that brief individual or group treatment with professional therapists can lead to reductions in self-reports of caregiver distress. Greene and Monahan recruited family caregivers living in the community whose levels of stress placed their elderly care recipient at risk for being institutionalized. Significant reductions in caregiver anxiety, depression, and burden were observed following 8 weeks of group counseling that contained educational and relaxation components. Another family caregiver study demonstrated that nursing home placement could be delayed significantly when a long-term family intervention program was utilized.⁷⁷ However, a number of caregiver studies have not collected follow-up data, and, when this information is available, there are inconsistent findings, especially in terms of maintaining improvement in psychological functioning over a period of time.

Support groups for caregivers of persons with dementia are available throughout the world. Again, while there are many anecdotal observations on the benefits caregivers receive from sharing experiences and information with their peers, there has been little empirical research to date.

Respite care falls into this same category of family interventions that have not been thoroughly examined and researched. For some time, professionals working with families have observed the benefit that respite care provides. Respite care enables a family member to have "time-off" from their caregiving responsibilities and comes in a variety of forms. Assistance with personal care by a home health aide, a volunteer sitter, or the opportunity to take a care recipient to an adult day program are examples of respite care. Unfortunately, there have been few empirical studies or outcome measure initiatives developed to research the efficacy of respite care services.⁷⁷

Behavioral interventions

The appropriate utilization of interventions in individuals with BPSD depends on a number of variables, including where the person is in the progression of the disease. For example, in the early stage, common symptoms include depression, anxiety, and loss of self-esteem. Recommended treatment could be psychotherapy, participation in an early-stage dementia support group, and reality orientation. In middle-stage dementia, behavioral problems often occur and the family begins to seek assistance through services such as home care and adult day care. Psychotherapy is usually not an effective intervention in an individual with dementia at this stage because it is dependent on memory retention and insight. Instead, validation therapy may provide an appropriate approach to middle stage when the patient has BPSD.

In the later stages of dementia, the person becomes extremely dependent, requiring a high level of assistance with toileting and personal hygiene. Therapeutic touch and the use of soothing music may provide the reassurance needed to avoid a catastrophic reaction. It is during this stage that most families look to long-term care facilities for providing appropriate care. There is a growing interest in the use of psychosocial interventions to help ease some of the adjustment problems associated with long-term residential care. Common interventions include reality orientation and validation therapy.

Psychotherapy

The vast majority of controlled, experimental outcome studies on psychotherapy with aging adults fall into one of two broad categories: (i) psychoeducational; or (ii) cognitive-behavior therapy (CBT). Psychoeducational therapies emphasize psychological theories and techniques. In contrast, CBT is an approach that combines the conceptual and applied work of various cognitive and behavioral learning models. CBT has been researched with geriatric outpatients and inpatients, medically stable and unstable older adults, and in group and individual intervention settings with aging adults. There is also a small but increasing amount of research literature suggesting that CBT is an effective treatment for depression in elderly patients. These interventions emphasize cognitive training, sensory stimulation, and physical rehabilitation, rather than improvements in social functioning.

Reality orientation

Reality orientation (RO) was developed in the United States in the 1960s. It is a basic technique used to rehabilitate persons having some form of memory loss, confusion, and disorientation in time, place, and person. RO has two formats: 24-hour RO and classroom RO. Classroom RO is an intensive cognitive retraining program conducted for about 30 minutes each day; 24-hour RO involves active orientation information cueing by all staff at every opportunity. RO, however, is beneficial only as long as the resident has the capacity to retain current information. Persons in the middle to late stage of dementia will not benefit from RO, and in some instances can become frustrated and agitated when asked RO-type of questions.

Validation therapy

Validation therapy was developed by Naomi Feil in 1982. It is an individual and group intervention that focuses on the emotional content of what someone is saying versus the factual content. The therapist validates what someone is saying by acknowledging the emotion(s) being expressed by the person (also referred to as "subjective reality"). This type of therapy has been observed to work especially well with memory-impaired persons such as those with dementia.⁸³

Reminiscence and life review

Up until the 1960s, reminiscing by older adults was not considered a healthy sign of aging. In 1961, however, Butler formulated the concept that reviewing one's life

may be a positive form of placing experiences in proper perspective and working through unresolved conflicts.⁸⁴ Empirical trials have been conducted using reminiscence and life review to reduce depression and anxiety and to increase feelings of self-esteem and life satisfaction in the elderly. Although results have been promising, findings have been inconsistent.⁸⁵ A number of variables may contribute to these differing impact rates such as the frequency and duration of the intervention, patient age, the setting (ie, a private residence or a long-term care facility), what measures of change are being used to assess treatment outcomes, whether the format is for individual or group therapy, and the use of other external stimuli such as music.⁸⁶⁻⁹¹

Reminiscence therapy has become a popular form of treatment in individuals with dementia because it depends more on personal experience than a factual recall of events. 92.93 Also, reminiscence can help patients come to terms with their situation, especially in the early stages of the disease when long-term memory of distant events is relatively preserved compared to short-term memory or the ability to recall recent events. Reminiscence or life review focuses on something the patient can still do and helps to maintain a sense of identity.

The evidence for the effectiveness of reminiscence in individuals with dementia is generally positive. One study of 27 nursing home residents with dementia indicated that the self-reported level of depression in reminiscence group participants was positively affected compared with participants in the supportive therapy and control groups. While there were no significant effects found for cognitive or behavioral functioning, the study results indicated the applicability of reminiscence therapy with persons with dementia.⁹⁴

Therapeutic activities and creative arts therapies

Therapeutic activities and the creative arts therapies have been recognized as beneficial, especially in persons with dementia living in long-term care facilities. Therapeutic programming emphasizes a balance of group and individual activities that promote strengths, personal interests, and abilities, as well as accomplishments, and the opportunity for self-expression. Creative arts therapies include music, art, dance/movement, drama, and bibliotherapy (literature and poetry).

A creative arts therapy is the controlled use of an art medium in the treatment, rehabilitation, education, and training of persons with physical, mental, and emotional disorders. For example, music has been recognized as a therapeutic tool with documented psychological and physiological effects for persons with dementia. ⁹⁵ Cohen-Mansfield et al reported reduced screaming in a study of nursing home residents where music was a part of the environment. ⁹⁶ Knopman and Sawyer-DeMaris found that music is usually preferred and enjoyed by patients with dementia in contrast to background noise from a television. ⁹⁷ (See section on Environment.)

Music interventions can be used in conjunction with exercise, as well as reminiscence and RO. Because people naturally move rhythmically, tap their feet, and clap their hands "in time" to the music, this medium can be used to increase movement in patients with limited range of motion. However, in attempting to find the appropriate balance of stimuli for the persons with dementia, it is critical that the type of music and volume level be selected carefully.

Therapeutic touch

An ancient intervention that has recently gained popularity in the field of health care is the use of therapeutic touch. In a survey of nursing home management of disruptive behavior, 38% of staff listed touch as an intervention. While few empirical data exist, a number of long-term care settings that offer professional massage therapy and whirlpool treatments indicate how beneficial this service has become. The use of touch with infants and autistic children has been documented; however, empirical studies of this intervention with the elderly are needed.

The environment

The term "environment" is used here in the most global sense to encompass everything from physical modifications to staff attitudes, approaches, and demeanor. This is commonly referred to as the therapeutic "milieu." A therapeutic milieu considers "problem behaviors" as meaningful expressions representing unmet needs and responds to these needs by using supportive interventions. A central element that can determine the effectiveness of a therapeutic milieu is the quality of all interactions that take place within the setting. This includes interpersonal interactions as well as individual actions and reactions to one's surroundings.

The physical environment of any living situation has the potential to be used as a therapeutic tool. Gunderson formulated a model that provides a "blueprint" of the therapeutic processes in psychiatric milieus. ⁹⁹ The model describes five elements that effect the therapeutic environment: safety, structure, support, involvement, and validation.

The environment also can be a source of intense frustration and insecurity, especially for patients with AD. The environment plays a significant role as an individual's level of impairment increases. There is no "perfect environment" for dementia sufferers, but two key factors that are responsible for an effective environment are creativity and flexibility. There is a growing amount of literature on design elements for individuals with dementia. However, given the individuality of the disease and its progression, there exists little empirical research and few protocols on which design practices work best under what circumstances.

Behavioral environmental approaches

Individuals with AD can have symptoms that may include paranoia, depression, and severe agitated behaviors such as hitting, kicking, screaming, and self-injury. These additional manifestations are often major risk factors for caregiver distress and nursing home placement. An alternative approach to the treatment of individuals with dementia who have severely agitated behavior is the use of behavioral environmental techniques, implemented in conjunction with, or in place of, traditional pharmacological treatments. 102

A behavioral environmental approach involves careful assessment of the current living environment and the behavior of the patients with dementia. This involves analyzing the behavior of persons that he or she interacts with on a fairly regular basis, such as family members, paid caregivers, and friends. For example, a home environment with a high level of stimulation (ie, television, radio, lights, furniture, pets, etc) can cause increased agitation in a person with dementia. Additionally, an untrained caregiver could provoke a catastrophic reaction from the person with dementia by demanding a level of performance that is not possible due to the dementing process. A behavioral environmental approach would be to eliminate or decrease the amount of unnecessary stimulation, such as background noise, and provide caregiver training on the limitations of the disease, as well as specific approaches to maximize the care recipient's level of functioning.

Behavioral intensive care units

Intensive care units were developed in the late 1950s and early 1960s in response to the perceived need for an increased level of observation and recording of critically ill medical and surgical patients. ¹⁰³ This model of care demonstrated that a person in an environment where variables are closely monitored, and prompt treatment is designed and implemented, had a significant improvement in survival rate and quality of life. ¹⁰⁴

Behavioral intensive care units (BICUs) are designed on the model described above, and therefore assume that agitated behaviors, especially in persons with dementia, are not random acts. Instead, this behavior is determined by either undetected medical problems (such as asymptomatic urinary tract infections or pneumonia) or elements in the environment that trigger, sustain, or extinguish the observed behavior. The elements of triggering, sustaining, or extinguishing agitated behaviors vary from individual to individual as well as from behavior to behavior.

The BICU strategy calls for intensive behavioral mapping and treatment. The treatment consists of two steps: (i) design and implementation of therapeutic interventions; and (ii) modification of the environment to which the person will return, including caregiver training. The therapeutic interventions are designed to achieve two goals: (i) modify the stimuli that cause the agitated behavior (environmental, medical, and/or psychiatric), and (ii) if the stimuli causing the behavior cannot be extinguished, then the social and physical environment is modified in such a way that the targeted behavior can be accepted.

BICU goals are achieved by placing the person with the agitated behavior(s) in a short-term unit where a thorough medical, psychiatric, and functional assessment is conducted. The agitated behavior(s) is specifically identified and evaluated. An individualized treatment plan is designed, implemented, and continually assessed. Discharge planning should begin at the time of admission and the return environment be assessed and modified as necessary. Family/caregiver education, training, and counseling should be provided. Follow-up visits to the home after discharge can be well suited to evaluating the effectiveness of the BICU interventions.¹⁰²

Restraint-free environments

As the 1990 Nursing Home Reform Act states: "The resident has the right to be free from any physical restraints imposed for the purpose of discipline or convenience and not required to treat the resident's medical symptoms." ¹⁰⁶

The use of physical restraints in nursing homes has long been debated among staff, physicians, administrators, and advocates for the elderly.¹⁰⁷ Even before the Federal regulations were enacted in 1990, there was a grassroots movement exploring the use of such restraints. The Kendal Corporation, a nonprofit entity that manages several nursing homes, had successfully operated these facilities as restraint-free environments for many years. In 1991, Kendal initiated "Untile the Elderly," a project to increase awareness and educate others throughout the country on how to become a restraint-free facility. Traditionally, the rationale for using physical restraints includes the concern for safety risks such as falls, the need to prevent self-injury, legal liability issues, and trying to compensate for inadequate or untrained staff. However, there are no scientific data to suggest that restraints prevent falls.¹⁰⁸ Conversely, in facilities where restraint use has been decreased or eliminated, the incidence of injuries from falls has decreased. 109

Few people are aware of the adverse and even harmful effects of physical restraint. The physiological effects of simple immobility caused by restraints have been well characterized. 110,111 Immobility causes decreased muscle mass, which results in weakness, loss of balance, and, along with bone demineralization, increases the risk of falls and fractures. Additionally, the metabolic rate slows, and circulatory responses can include decreased cardiac output, increased risk of blood clots, and orthostatic hypotension. Any of these conditions can create a decreased breathing volume, which can result in pneumonia, a leading cause of death in the elderly. Common side effects of immobility include constipation, increased skin breakdown and infections, and increased confusion. There have been no successful legal claims against longterm care facilities based solely on the failure to restrain a resident.112 Additionally, it is believed that the movement of Federal regulations towards the least-restrictive environment possible will impact future liability claims. Finally, it is unrealistic to believe that it takes less time to supervise and protect a resident in restraint. Studies by Blakeslee et al have determined that residents in restraints actually take an estimated 4.58 hours per day of personal attention to comply with restraint standards of care, compared with 2.7 hours per day of personal attention needed when the restraints were removed.¹⁰⁹

The initial step to changing the use of restraints must involve all levels of staff, including physicians, administrators, and nonnursing staff. Written guidelines should clearly state the facility's policy and these should be shared with all staff, family members, volunteers, visitors, funding sources, and regulators. A second step involves education and replacing myths with accurate information. The final step is identifying alternative options for managing and accepting the resident's behavior. There is no one "right" answer, but staff should be encouraged to develop, implement, and assess innovative approaches. Alternatives to physical restraints often fit into one of four categories: medical treatment, environmental modifications, behavioral interventions, and rehabilitative measures.¹¹³

Special care units

The Office of Technology defines these as specially designed environments with skilled staff to provide ongoing care and programs addressing the special needs of patients with Alzheimer's disease. There has been a growing trend for nursing homes to offer specialized programming for residents with dementia. Termed "special care units" (SCUs), these programs vary enormously from specifically designed freestanding facilities with highly trained staff to institutions that simply have one wing that segregates residents with dementia from the physically frail.

The first SCU opened in 1974 at the Philadelphia Geriatric Center. In 1992, at least 10% of all nursing homes indicated that their facility offered an SCU. Approximately 15% to 25% of these same facilities reported that they charged a higher rate for the SCU. In 1994, there were over 1500 SCUs in the US caring for about 50 000 residents. It is projected that these numbers will increase geometrically in the near future. 114

An SCU should exemplify the most current state-of-the art environment. This involves utilizing the nonpharmacological interventions previously described. However, a 1994 study conducted by the Alzheimer's Association and the University of Iowa produced some unsettling information.¹¹⁵ The study involved the extensive interviewing of

112 state long-term care ombudsmen, 61 directors of state nursing home licensing agencies from 29 states, and 453 family members who have or had a family member in a special care unit. The major findings were:

- The professional advocates reported little difference between SCUs and traditional nursing homes. While there were few serious problems, a majority of these professionals said that most of the SCUs were no better than other nursing homes in the very features that should distinguish "special care," ie, specialized activities, sufficiently trained staff, the absence of involuntary seclusion of residents, and the ability to manage challenging behaviors.
- One third of the families said they paid more for SCUs and one third said they did not know if they were paying more. This is problematic, especially if there is little or no difference in the care provided by these units.
- Nearly all family members reported satisfaction with staff attitudes and safety precautions and the majority would place their family member in the same SCU again.
- A majority of the professional advocates favored the creation of rules governing the operation and evaluation of SCUs.¹¹⁴

Individuals with dementia need additional consideration with regard to staffing, environmental considerations, level of stimuli, and safety. Traditionally, nursing homes were often unable to meet these special needs adequately, hence the development of SCUs. However, a number of issues surrounding SCUs need further exploration and resolution. Some professionals believe that the benefits from clustering persons with dementia in separate areas are outweighed by the stigma of segregation, the lack of higher functioning persons as role models, and the absence of established protocols for dementia care. Additionally, a number of these units lack specific admission and discharge criteria, thus reinforcing the belief held by some that SCUs are simply "repackaging" traditional nursing home care for AD families. The National Institute on Aging has been conducting a nationwide longitudinal study of SCUs for several years. However, preliminary data have been inconclusive regarding the efficacy and cost-effectiveness of these programs.

Professional caregiver stress

The psychological stress of caregiving has been well documented. A review by Schultz et al thoroughly evaluated the existing empirical literature that described the prolonged consequences of caregiving.⁷³ The adverse mental health consequences were frequent, particularly the development of depression, anxiety, and hostility or anger. There also exists a significant amount of research on stress or "burnout" in people in various helping professions, including nursing home staff and staff caring for persons with dementia.¹¹⁶⁻¹²¹

Stress is the combination of the body's physical, mental, and chemical responses to demands. Occupational stress has been defined as the psychological or physical discomfort associated with work that is characterized by heavy demands and limited control over working conditions.¹¹² Nursing home employees have been found to be at significant risk for high levels of occupational stress. Contributing factors include the physical and emotional demands of the work, the negative perception of longterm care is reinforced by low wages, and few options for career advancement and/or recognition. Consequences of this stress include the adverse mental health states previously mentioned as well a loss of self-esteem, loss of mastery or control over work situations, and increased absenteeism, lateness, utilization of sick leave and health benefits, and staff turnover. In addition, stressed caregivers may stereotype the elderly. 122 This can lead to diminished expectations about the nursing home resident, and the transference of this belief onto the resident.123 Stressed caregiver behaviors also include childlike treatment of residents, indiscriminate restraint use, and physical and verbal abuse.117

Self-care interventions

Learning ways to reduce and handle chronic stress requires a change in lifestyle. Stress reduction techniques can range from very simple to highly specialized biobehavioral treatment. A holistic approach to reducing stress should include learning new coping skills, such as the ability to set limits, problem solving, and the practice of positive thinking. The overall goal should be a healthy lifestyle that combines self-care interventions as well as opportunities for education, support, and a responsive work environment.

One popular stress-relieving technique is known as the relaxation response. This response produces a relaxed state with reduced breathing and heart rate. A relaxed state is accomplished by sitting quietly, closing one's eyes, while relaxing muscles progressively from the feet to the head

and breathing deeply for 15 to 20 minutes.¹²⁴ Other similar interventions include imagery techniques such as visualization, guided imagery, active remembering, meditation, chanting, channeling, and listening to calming music.

A healthy lifestyle includes a balanced diet, regular exercise, and adequate rest. A nutritionally sound diet should limit alcohol, caffeine, and sugar intake. Also to be avoided are skipped and hurried meals, as well as chronic dieting. Exercise has been found to be a stress reliever. Exercise releases endorphins into the blood stream, which naturally assist the body to relieve stress.¹²⁵

Staff training and support

Personal and professional caregivers need to continually update and enhance their knowledge. Long-term care facilities should provide staff with ongoing education, training, and support. Moos and Schaefer found that occupational stress can be impacted by the level of social support staff perceived from their coworkers and supervisors.¹²⁶ A growing number of long-term care facilities offer support groups for employees. The purpose of these groups is to provide opportunities for expressing feelings, sharing information, and gaining new insight and understanding. Additionally, the utilization of resident-centered strategies with a multidisciplinary team approach can be effective in resolving stressful caregiving situations. Inclusion of the resident and the family, whenever possible, can further the establishment of realistic expectations and the opportunities to view the resident as a unique individual and not as a "behavior problem." 123

Workplace environment

Productivity studies have traditionally recognized the effects of physical features such as lighting, noise, and workstation features on efficiency and accident rates. However, research on stress in the helping professions has primarily focused on relationships within the work group and between management and employees. The effect of the physical environment has only recently begun to be explored.

One recent study looked at twelve AD adult day care centers and the impact of the workplace environment on staff.¹²⁷ The results of the study found that work stress can be managed in the AD care setting if the demands of working with a cognitively impaired population can be minimized and staff member, have some degree of con-

trol over their environment. Staff members identified four specific aspects of the workplace environment that impacted occupational stress: space and spatial arrangements, security and wandering features, bathrooms/personal care space, and staff space/ privacy. The following recommendations are based on the authors' own experience in providing AD care and confirmed in the findings from the study conducted by Lyman et al.¹²⁷

Space considerations should include the avoidance of congestion, especially in transitional areas such as halls, reception areas, and in front of rest rooms. Traffic flow can be hampered when it is unclear to participants how to get from one area to the next. Staff members may have to spend inordinate amounts of time simply moving patients from one area to the next. It is also important to have smaller rooms as well as group activity space. Extremely large open spaces such as "day rooms" can be overwhelming for the cognitively impaired, and are difficult to control in terms of noise level and privacy. An ever-present concern in providing care in AD is the safety of potential wanderers. In facilities where security systems are inadequate, much of the workday is dominated by the anxiety produced by the fear that residents may become lost or leave the facility unattended. When rest rooms are inconveniently located, it can require one-on-one staffing in order to adequately meet residents' personal needs. residents who might independently find and use the bathroom may become unnecessarily dependent when personal care facilities are poorly designed and located.

Inadequate space is often problematic in facilities. This includes space for storage, personal belongings, and privacy. The work becomes stressful when there is no provision for a staff area with some degree of visual and acoustic privacy. As one staff member said, "A break really isn't a break when there is no place to get away for awhile." Also, it is difficult to properly support employees when there is no private space for supervisory discussions, and other work-related conversations that require confidentiality and privacy.

Other environmental considerations should include outdoor space for staff and residents. Also, way-finding cues such as brightly colored bathroom doors, and defined wandering paths offer greater independence for confused persons and, in turn, reduce demands on staff. Furthermore, when staff are involved in environmental modifications there is an increased sense of control over working conditions.

Signos y síntomas conductuales y psicológicos de la demencia: un punto de vista del psiquiatra clínico

La Enfermedad de Alzheimer se presenta típicamente como dos síndromes que se sobreponen, uno cognitivo y otro conductual. El síndrome conductual se caracteriza por psicosis, agresividad, depresión, ansiedad, agitación y otros síntomas frecuentes, -pero no bien definidos- que se agrupan bajo la denominación genérica de "síntomas conductuales y psicológicos de la demencia" (SCPD). Este síndrome se divide a su vez en varios subsíndromes: psicosis, trastornos del ritmo circadiano (sueño-vigilia), depresión, ansiedad y agitación. Son los SCPD los que afectan a los cuidadores de estos pacientes y en definitiva los que precipitan la cadena de acontecimientos que llevan muchas veces a tener que hospitalizar al paciente en alguna institución por tiempo prolongado. El desafío terapéutico consiste en eliminar las posibles causas médicas ocultas (fractura de cadera no diagnosticada, infección urinaria asintomática o una neumonía). Las intervenciones farmacológicas incluyen la risperidona y -cada vez con mayor frecuencia- los inhibidores de la colinesterasa para el control de la psicosis (aunque la frecuencia de respuesta favorable es de sólo un 65% con dosis tolerables); olanzapina, risperidona y citalopram para la ansiedad y, carbamazepina y ácido valproico para la agitación. Sin embargo, existen evidencias crecientes a favor de intervenciones no farmacológicas, las que podrían llegar a ser consideradas como la base del tratamiento de los SCPD. Los trastornos de conducta pueden ser enfocados como respuestas significativas a necesidades insatisfechas en el medio terapéutico. Ya que la progresión e impacto de los SCPD varían entre los pacientes, las intervenciones deben ser exploradas, diseñadas, implementadas y evaluadas en forma individual. Estas intervenciones incluyen soporte y educación familiar, psicoterapia, orientación a la realidad, terapia de validación, recuerdos y revisión de la vida, intervenciones conductuales, actividades terapéuticas y terapias artísticas creativas, consideraciones ambientales (incluyendo espacios de libre desplazamiento), unidades de cuidados intensivos conductuales y, diseño de lugares de trabajo y prácticas que ayuden a los cuidadores profesionales al manejo continuo del estrés.

Les signes et symptômes psychologiques et comportementaux de la démence : le point de vue du psychiatre

La maladie d'Alzheimer se manifeste typiquement par deux syndromes fréquemment imbriqués, l'un cognitif, l'autre comportemental. Le syndrome comportemental associe psychose, agressivité, dépression, anxiété, agitation ainsi que d'autres symptômes fréquents quoique moins bien définis. L'ensemble de ces manifestations est regroupé sous l'entité générale "symptômes comportementaux et psychologiques de démence" (SCPD), elle-même divisée en plusieurs sous-syndromes : psychose, troubles du rythme circadien (veille-sommeil), dépression, anxiété et agitation. C'est le SCPD, avec son retentissement sur les personnes prenant en charge ces patients, qui précipite la succession des événements aboutissant à l'hospitalisation en long séjour. Toute la difficulté thérapeutique consiste à traiter les situations restées sans médicalisation, telles une fracture de hanche non diagnostiquée ou une infection urinaire ou une pneumonie asymptomatiques). Le traitement pharmacologique de la psychose repose sur la rispéridone et, de plus en plus, sur les inhibiteurs de la cholinestérase (mais avec un taux de réponses de 65 % seulement aux doses tolérées), tandis que l'anxiété est traitée par l'olanzapine, la rispéridone et le citalopram, et l'agitation par la carbamazépine et l'acide valproïque. Néanmoins, de plus en plus d'arguments militent en faveur de l'approche non pharmacologique, au point que celle-ci doit désormais être considérée comme le traitement de fond du SCPD. Les troubles du comportement sont considérés comme des réponses significatives à des besoins insatisfaits par la prise en charge thérapeutique. Comme l'évolution et l'impact du SCPD varient selon les patients, les mesures à prendre doivent être examinées, choisies, appliquées et évaluées de façon individuelle. Celles-ci comprennent : le soutien familial et l'éducation, la psychothérapie, l'orientation par rapport à la réalité, la thérapie par validation, l'évocation de la vie antérieure et des réminiscences, les thérapies comportementales, les activités thérapeutiques et l'art-thérapie, l'aménagement de l'environnement (y compris des équipements qui ne doivent plus recourir aux entraves physiques), le développement d'unités de soins intensifs du comportement, et l'adaptation du lieu de travail, sans oublier les mesures visant à faciliter la prise en charge continue du stress des professionnels de santé.

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