

# Behavioral and Psychological Symptoms of Dementia (BPSD) Educational Pack



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## MODULE 1: An Introduction to BPSD

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## ***Key messages***

- With the aging of the world's population, a significant increase in the absolute number of elderly with Alzheimer's disease (AD) and other irreversible dementias is now taking place.
- Dementia is associated with progressive cognitive disability, a high prevalence of behavioral and psychological symptoms of dementia (BPSD) such as agitation, depression and psychosis, stress in caregivers and costly care.
- BPSD are an integral part of the disease process and present severe problems to patients, their families and caregivers, and society at large.
- BPSD are treatable and generally respond better to therapy than other symptoms or syndromes of dementia.
- Treatment of BPSD offers the best chance to alleviate suffering, reduce family burden and lower societal costs in patients with dementia.

## ***Importance of BPSD***

### **The aging of the world population**

The number of elderly people in the world is rising steeply. For example, the increase in people aged  $\geq 80$  years in developed countries between 1975 and 2000 has been estimated at 65% (United Nations, 1988). For the less developed world, this increase is 138% – a reflection of the improvements in healthcare and nutrition that have come to much of the world's population in the second half of the twentieth century. As these numbers increase over the next 30 years (Figure 1) there will be a dramatic rise in the number of people with dementia. In 2000, it was estimated that there were 18 million people with dementia in the world, 11 million of who lived in the developing world. Projections for 2025 are that these numbers will reach 34 million worldwide and 25 million in developing countries.

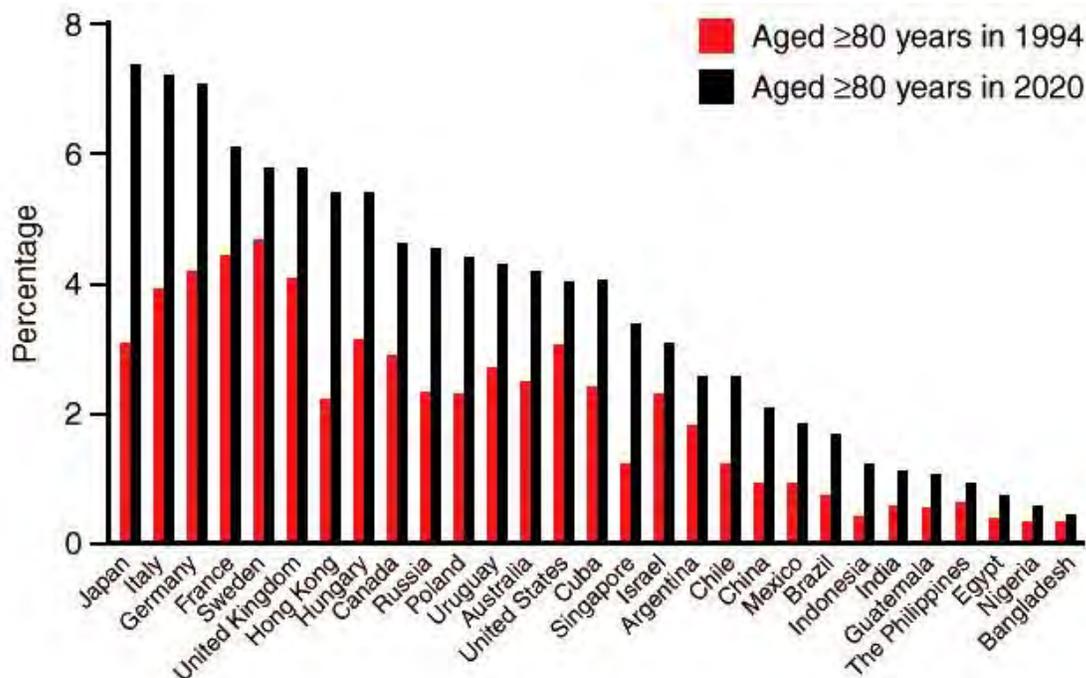


Figure 1. Estimations of the increasing size of the elderly population

Disabilities and dementias increase markedly in the over 80-year-old population. Over the age of 75 years, the annual incidence of AD is about 1%, increasing to approximately 10% at age 85 (Bachman et al., 1990). The prevalence of AD has been reported to be between 5 and 7% in those over the age of 65 years (Folstein et al., 1985; Sulkava et al., 1985; Copeland et al., 1987). In the very elderly, the prevalence is between 12% at age 85–90 years (Kay, 1991), and 47% at age 85 years and over (Evans et al., 1989).

These increases have major implications for the provision of healthcare generally and for dementia care in particular. If more people have dementia, there will be more people exhibiting behavioral and psychological symptoms of dementia. This constitutes the greatest burden to caregivers. This module describes these important aspects of dementia, as well as their frequency and impact.

### ***BPSD in classic descriptions of dementia***

BPSD have been identified as integral parts of dementing disorders from the earliest descriptions of these conditions. For example, in defining the ‘dementia senile’ in 1838, Esquirol noted that it is a condition, which may be accompanied by emotional disturbances (Esquirol, 1838).

Alois Alzheimer, in his classic early twentieth century case description of the disease, now universally associated with his name, noted behavioral symptoms as prominent manifestations in his brief case description (Alzheimer, 1906). The symptoms included:

- paranoia
- delusions of sexual abuse
- hallucinations
- screaming.

Vascular dementia (previously called multi-infarct dementia) also has emotional instability and BPSD as prominent features. BPSD, including aggressive behavior and visual hallucinations, are seen in Lewy body dementia.

Consensus definitions of AD have generally included behavioral descriptions. The American Psychiatric Association's Fourth Edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) describes subtypes of the disorder depending on the presence of delusions or depression. In addition, rating scales such as the Blessed Dementia Scale and the Sandoz Clinical Assessment Geriatric Scale (SCAG) that have traditionally been used for the assessment of dementia have incorporated BPSD as elements of the condition.

### ***Emerging recognition of BPSD***

The focus on BPSD began in earnest only in the 1980s. Some investigators attributed BPSD to neurotransmitter or neuropathologic changes whereas others have focused more on personality contributors and psychosocial factors (see Module 3).

It is clear that BPSD need to be assessed as part of an evaluation of dementia. Since 1986, there have been a number scales developed to evaluate BPSD (see the box below for some examples and the Appendix for a full list).

#### **1986**

The Cohen-Mansfield Agitation Inventory (CMAI) focused specifically on behaviors such as hitting, pacing and screaming (Cohen-Mansfield et al., 1989; Cohen-Mansfield, 1996).

#### **1987**

The Behavioral Pathologic Rating Scale for Alzheimer's disease (BEHAVE-AD) focused on specific symptoms in AD, different from those seen in other neuropsychiatric disorders, such as delusion that people are stealing things, fear of being left alone and fragmented sleep. (Reisberg et al., 1996).

#### **1994**

The Neuropsychiatric Inventory (NPI) has frequency and severity scales for behaviors common to AD, but also includes scales for other dementias (Cummings et al., 1994).

#### **1995**

The Consortium to Establish a Registry in AD (CERAD) Behavioral Scale focused on both behavioral and psychological symptoms (Tariot et al., 1995; Tariot, 1996).

### ***Modern definition of BPSD – a consensus statement***

In 1996, the International Psychogeriatric Association (IPA) convened a Consensus Conference on the Behavioral Disturbances of Dementia for two purposes:

- to review current knowledge on behavioral disturbances of dementia
- to reach some consensus of opinion in four critical areas:
  - definition of the symptoms
  - causes of the symptoms
  - description of clinical symptoms

- research directions.

The 1999 Update Consensus Conference provided additional knowledge and new research directions.

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- The Consensus group, consisting of some 60 experts in the field, from 16 countries, produced a statement on the definition of the BPSD: “The term behavioral disturbances should be replaced by the term behavioral and psychological symptoms of dementia (BPSD), defined as: Symptoms of disturbed perception, thought content, mood or behavior that frequently occur in patients with dementia. (Finkel & Burns, 1999)
- 

There are many ways in which BPSD can be grouped. The participants of the Consensus group recognized that for certain purposes it might be useful to group them into specific symptom clusters (e.g., depressive syndrome, psychotic syndrome). A simple method of grouping is shown in the box below.

<i>Behavioral symptoms</i> Usually identified on the basis of observation of the patient, including physical aggression, screaming, restlessness, agitation, wandering, culturally inappropriate behaviors, sexual disinhibition, hoarding, cursing and shadowing.
<i>Psychological symptoms</i> Usually and mainly assessed on the basis of interviews with patients and relatives; these symptoms include anxiety, depressive mood, hallucinations and delusions. A psychosis of Alzheimer's disease has been accepted since the 1999 conference.

The clinical presentation of the BPSD is covered in detail in Module 2. In the United States one syndrome derived from BPSD is the Psychosis of Alzheimer's Disease (Jeste & Finkel, 2000).

### ***Frequency and impact of BPSD***

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- BPSD can result in suffering, premature institutionalization, increased costs of care, and significant loss of quality-of-life for the patient and his or her family and caregivers (Finkel et al., 1996).
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A number of studies looking at the occurrence of BPSD in nursing home populations have found these symptoms to occur in up to 90% of patients (see Table 1).

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*Table 1. The prevalence of BPSD. Reprinted with permission from Finkel, 1998*

<b>Sign or symptom</b>	<b>Reported frequency (% of patients)</b>
<i>Perceptual</i>	
Delusions	20–73
Misidentifications	23–50
Hallucinations	15–49
<i>Affective</i>	
Depression	up to 80
Mania	3–15

Sign or symptom	Reported frequency (% of patients)
<i>Personality</i>	
Personality change	up to 90
Behavioral symptoms	up to 50
Aggression/hostility	up to 20

Various BPSD occur at different phases of illness. Research has indicated that these symptoms either:

- appear to occur increasingly as the dementing disorder progresses or,
- may occur more commonly during specific periods in the dementing disorder.

Wandering and agitation have been shown to be the most enduring BPSD over a 2-year period (Devanand et al., 1997).

Untreated BPSD contribute to:

- premature institutionalization (Colerick and George, 1986; Morriss et al., 1990; Steele et al., 1990; O'Donnell et al., 1992)
- increased financial cost (Cohen-Mansfield, 1995)
- decreased quality of life for both the caregiver and the patient (Deimling and Bass, 1986; Burgio, 1996)
- significant caregiver stress (Rabins et al., 1982)
- stress to nursing staff in residential facilities (e.g. Rodney, 2000; Draper et al, 2000)
- excess disability (Brody, 1982), i.e. people with BPSD function at a lower level than those without. Once symptoms are ameliorated or removed, functional level improves (reducing patient and caregiver distress and improving quality of life).

### ***Development of specific therapies for BPSD***

In the 1990s there was increased interest in specific therapies for BPSD for several reasons:

- BPSD are recognized as major sources of burden for caregivers of patients with dementia and are frequently cited by caregivers as reasons for institutionalization of their relatives
- determination of the impact of pharmacological and non-pharmacological interventions in treating BPSD became an area of active scientific research and investigation
- previously, clinicians had attempted to treat BPSD with various medications in the absence of data regarding their efficacy. Data became available to help guide therapy.

There are many reasons why good research data were previously lacking. Demented, elderly patients were considered a 'difficult' study population because of their age and frailty, and the nature of their illness. Until the last decade there were no good methods to assess demented individuals. Available research now shows that the majority of demented persons with psychosis, agitation or anxiety improve with appropriate treatment (Schneider et al., 1990; Finkel et al., 1995).

In recent years, governments, the pharmaceutical industry and research foundations have become interested in BPSD and efforts to measure the outcome of treatment in terms of quality of life and cost-effectiveness are increasing.

## ***Quality-of-life assessment***

Recently, there have been attempts to measure quality of life in elderly persons with dementia. Such assessments include evaluation of the following items:

- health status (including health-associated disabilities)
- environment (including restrictions, stigma, opportunity for choice)
- subjective perceptions of mood, physical discomfort and frustration
- behavioral observation of activity, affect and social involvement
- caregiver reporting of behavior and mood.

## ***Pharmacoeconomic assessment***

Pharmacoeconomic assessment of treatment interventions (a kind of cost effectiveness measurement) is an important part of decision-making in healthcare. This is particularly true for BPSD because the increased demand for effective interventions has significant consequences for private and public healthcare budgets.

To obtain an accurate picture of the true costs and benefits of an intervention (e.g., pharmacological or non-pharmacological treatments, environmental alterations), pharmacoeconomic studies must measure many factors. These include: increased length of hospitalization for the demented medically ill elderly; premature institutionalization in a nursing home; and improvement or deterioration in symptoms.

Clinicians in most countries now find they must consider the economic costs and benefits of particular drugs as well as the drug's effectiveness and safety. New medications with benefits in terms of improved tolerability and safety profiles but with higher drug purchase costs often change the cost-benefit assessments. Current studies are focusing on these issues in dementia and will inform clinicians about which treatments are most appropriate for specific symptoms.

## ***Future directions: research***

Advances in understanding BPSD depend on investigating their phenomenology, origins, course, pathophysiology, social and environmental influences, and responses to treatment interventions.

Opportunities for research on BPSD are exciting because of new techniques and methods for the assessment of patients, as well as the availability of measurement scales specifically developed for this patient population. Research resources are unevenly distributed and unavailable in many countries. More research is needed to ensure a strong and productive research program (see box below).

Research now needs to address the following areas:

- development of cross-culturally applicable methods for the assessment of BPSD
- exploration of the relationship of BPSD to the environments in which they occur
- understanding of the underlying biological and psychological substrates
- longitudinal evaluation of these symptoms

- determination of the frequency, underlying pathogenic mechanisms, and clinical and social impact on patient, family, healthcare professionals and society of BPSD
- development of a well-defined profile of treatment methods with specific reference to different types of BPSD and the response of these BPSD to pharmacological and non-pharmacological interventions.

### ***IPA educational programs for BPSD***

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- The mission of the BPSD task force is:  
“The promotion of research, training and dissemination of information on behavioral and psychological symptoms of dementia [BPSD] to healthcare professionals and caregivers.”
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The goals of the BPSD educational programs are to:

- inform psychiatrists, neurologists, geriatricians, related healthcare providers and caregivers of the behavioral and psychological symptoms of AD and other dementias
- inform about the relationship between the symptoms and the course of the illness
- view the symptoms both individually and collectively in developing a specific plan for intervention
- describe what is known about current treatments and management
- describe and understand the specific needs of caregivers in relation to these symptoms
- view cross cultural and translation variations

Educational modalities include:

- publication in journals
- establishment of an international speakers' bureau
- slides and/or CD Rom
- an internet web site (Click “Interactive Education” for a quiz on the material in this module)

For more information about IPA educational programs for BPSD, please contact:

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## **Appendix: Rating scales for BPSD**

This Appendix lists commonly used rating scales for the assessment of BPSD. A reprint of these scales can be found either in the original reference given or in the Appendix to a special issue of *International Psychogeriatrics* 1996; 8 (Suppl 3).

### *Behavioral and Emotional Activities Manifested in Dementia (BEAM-D)*

Sinha D, Zemlan FP, Nelson S, et al. A new scale for behavioral agitation in dementia. *Psychiatry Res* 1992; 41: 73–88.

### *Behavioral Pathology in Alzheimer's Disease Rating Scale (BEHAVE-AD)*

Reisberg B, Borenstein J, Salob SP, Ferris SH. Behavioral symptoms in Alzheimer's disease: Phenomenology and treatment. *J Clin Psychiatry* 1987; 48 (Suppl): 9–15.

### *Blessed Dementia Scale*

Blessed G, Tomlinson BE, Roth M. The association between quantitative measures of dementia and of senile change in the cerebral grey matter of elderly subjects. *Br J Psychiatry* 1968; 114: 797–811.

### *Brief Agitation Rating Scale (BARS)*

Finkel SI, Lyons JS, Anderson RL. A brief agitation rating scale (BARS) for nursing home elderly. *J Am Geriatr Soc* 1993; 41: 50–52.

### *Caretaker Obstreperous Behavior Rating Assessment (COBRA)*

Drachman DS, Swearer JM, O'Donnell BF, et al. The Caretaker Obstreperous Behavior Rating Assessment (COBRA) scale. *J Am Geriatr Soc* 1992; 40: 463–480.

### *CERAD Behavior Rating Scale for Dementia*

Tariot PN, Mack JL, Patterson MB, et al. The behavior rating scale for dementia of the consortium to establish a registry for Alzheimer's disease. The behavioral pathology committee of the consortium to establish a registry for Alzheimer's disease. *Am J Psychiatry* 1995; 152(9): 1349–1357.

### *Cohen-Mansfield Agitation Inventory (CMAI)*

Cohen-Mansfield J, Marx MS, Rosenthal AS. A description of agitation in a nursing home. *J Gerontol* 1989; 44: M77–M84.

### *Cornell Scale for Depression in Dementia*

Alexopoulos GS, Abrams RC, Young RC, Shamoian CS. Cornell Scale for Depression in Dementia. *Biol Psychiatry* 1988; 23: 271–284.

### *Dementia Behavior Disturbance Scale (DBD)*

Baumgarten M, Backer P, Gauthier S. Validity and reliability of the Dementia Behavior Disturbance Scale. *J Am Geriatr Soc* 1990; 38: 221–226.

### *Dementia Mood Assessment Scale (DMAS)*

Sunderland T, Alterman I, Yount D, et al. A new scale for the assessment of depressed mood in dementia subjects. *Am J Psychiatry* 1988; 145: 955–959.

### *Dysfunctional Behavior Rating Instrument (DBRI)*

Molloy DW, McIlroy WE, Guyatt GH, Lever JA. Validity and reliability of the Dysfunctional Behavior Rating Instrument. *Acta Psychiatr Scand* 1991; 84: 103–106.

*Global Assessment of Psychiatric Symptoms (GAPS)*

Raskin A, Crook T. Global Assessment of Psychiatric Symptoms (GAPS). *Psychopharmacol Bull* 1988; 24: 721–725.

*Gottfries-Bråne-Steen Scale*

Gottfries C-G, Bråne G, Gullberg B, Steen G. A new rating scale for dementia syndrome. *Arch Gerontol Geriatr* 1982; 1: 311–330.

*Irritability/Apathy Scale*

Burns A, Folstein S, Brandt J, Folstein M. Clinical assessment of irritability, aggression, and apathy in Huntington and Alzheimer's disease. *J Nerv Ment Dis* 1990; 178: 20–26.

*Manchester and Oxford Universities Scale for the Psychopathological Assessment of Dementia (MOUSEPAD)*

Allen NHP, Gordon S, Hope T, Burns A. Manchester and Oxford Universities Scale for the Psychopathological Assessment of Dementia (MOUSEPAD). *Br J Psychiatry* 1996; 169: 293–307.

*Neurobehavioral Rating Scale*

Levin HS, High WM, Goethe K, et al. The Neurobehavioral Rating Scale: Assessment of the behavioral sequelae of head injury by the clinician. *J Neurol Neurosurg Psychiatry* 1987; 50: 183–193.

*Neuropsychiatric Inventory (NPI)*

Cummings J, Mega M, Gray K, et al. The Neuropsychiatric Inventory: Comprehensive assessment of psychopathology in dementia. *Neurology* 1994; 44: 2308–2314.

*Pittsburgh Agitation Scale*

Rosen J, Burgio L, Killar M, et al. The Pittsburgh Agitation Scale. *Am J Geriatr Psychiatry* 1994; 2: 52–59.

*Revised Memory and Behavior Problems Checklist*

Teri L, Truaz P, Logsdon R, et al. Assessment of behavioral problems in dementia: The Revised Memory and Behavior Problems Checklist. *Psychol Aging* 1992; 7: 622–631.

*Sandoz Clinical Assessment – Geriatric (SCAG)*

Shader RL, Harmatz JS, Salzman C. A new scale for clinical assessment in geriatric populations: Sandoz Clinical Assessment – Geriatric (SCAG). *J Am Geriatr Soc* 1974; 22: 107–113.

*Self-Psychology Rating Scale*

Lazarus LW, Cohler BL, Lesser J. Dissolution of the self in Alzheimer's disease – clinical implications. In: Bergener M, Finkel SI (eds). *Treating Alzheimer's disease and other dementias*. New York: Springer Publishing Co, 1995: 496–509.

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J Geriatr Psychiatry Neurol 1988; 1: 71–76.

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Copeland JR, Davidson IA, Dewey ME, et al. Alzheimer's disease, other dementias and pseudodementia: prevalence, incidence and three-year outcome in Liverpool. Br J Psychiatry 1992; 161: 230–239.

Copeland JR, Dewey ME, Wood N, et al. Range of mental illnesses among the elderly in the community. Br J Psychiatry 1987; 130: 815–823.

Cummings JL, Mega M, Gray K, et al. The Neuropsychiatric Inventory: Comprehensive assessment of psychopathology in dementia. Neurology 1994; 44: 2308–2314.

Deimling GT, Bass DM. Symptoms of mental impairment among elderly adults and their effects on family caregivers. J Gerontol 1986; 41: 778–784.

Devanand DP, Jacobs DM, Tang MX, et al. The course of psychopathology in mild to moderate Alzheimer's disease. Arch Gen Psychiatry 1997; 54: 257–263.

Esquirol JED. *Des Maladies Mentales*. 1938.

Draper B, Snowdon J, Meares S, et al. Case-controlled study of nursing home residents referred for treatment of vocally disruptive behavior. *Int Psychogeriatr* 2000; 12: 333-334.

Evans DA, Funkenstein HH, Albert MS, et al. Prevalence of Alzheimer's disease in a community population of older persons. Higher than previously reported. *JAMA* 1989; 262: 2551-2556.

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O'Donnell BF, Drachman DA, Barnes HJ, et al. Incontinence and troublesome behaviors predict institutionalization in dementia. *J Geriatr Psychiatry Neurol* 1992; 5: 45-52.

Rabins PV, Mace NL, Lucas MJ. The impact of dementia on the family. *JAMA* 1982; 248: 333-335.

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Rovner BW, German PS, Broadhead J, et al. The prevalence and management of dementia and other psychiatric disorders in nursing homes. *Int Psychogeriatr* 1990; 2: 13-24.

Steele C, Rovner B, Chase GA, Folstein M. Psychiatric symptoms and nursing home placement of patients with Alzheimer's disease. *Am J Psychiatry* 1990; 147: 8.

Sulkava R, Wilkstrom J, Aromaa A, et al. Prevalence of severe dementia in Finland. *Neurology* 1985; 35: 1025-1029.

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Schneider LS, Pollock VE, Lyness SA. A meta-analysis of controlled trials of neuroleptic treatment in dementia. *J Am Geriatr Soc* 1990; 38: 553–563.

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## MODULE 2: Clinical issues

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## ***Key messages***

- Behavioral and psychological symptoms of dementia (BPSD) are very common and are significant symptoms of the illness.
- Among the most intrusive and difficult BPSD to cope with are:
  - psychological symptoms of
    - delusions
    - hallucinations
    - misidentifications
    - depression
    - sleeplessness
    - anxiety
  - behavioral symptoms of
    - physical aggression
    - wandering
    - restlessness.

Moderately common BPSD which can also be distressing include:

- agitation
  - culturally inappropriate behavior
  - sexual disinhibition
  - pacing
  - screaming.
- BPSD that are common and upsetting, but that are more manageable and less likely to result in institutionalization include:
    - crying
    - cursing
    - apathy
    - repetitive questioning
    - shadowing (stalking).

## ***BPSD***

### **Clinical presentation**

Behavioral and psychological symptoms of dementia (BPSD) are very common and are significant symptoms of the illness, contributing most to caregiver burden and often resulting in premature institutionalization of the person with dementia (see Module 1).

Detailed studies of the occurrence of BPSD suggest that any symptom can occur during any stage in dementia and at certain stages virtually all patients demonstrate some type of BPSD (Reisberg et al., 1989). One study of BPSD found that 64% of patients with Alzheimer's disease (AD) had one or more BPSD at initial evaluation (Devanand, et al., 1997). The majority of these people were living at home. In a community based population survey using the Neuropsychiatric Inventory (NPI), Lyketsos et al. (Am.J. Psychiatry, 2000; 157:708-714) reported that people with dementia had over 40 times the rate of behavioral disturbance than did the rest of the population and 61% of people with dementia had at least one behavioral disturbance and 31% had severe levels of BPSD (defined as an NPI score of  $\geq 6$ ).

Characteristic BPSD are listed in Table 1. A historical review of the nosology or classification of BPSD is presented in Appendix 1. A variety of instruments have been developed to quantify BPSD, and theories behind existing rating scales are reviewed in Appendix B.

### **Duration and course**

As noted in Module 1, different BPSD occur during different phases of the illness. Affective symptoms are more likely to occur earlier in the course of the illness (Reisberg et al., 1989; Rubin et al., 1988). Agitated and psychotic behaviors are frequent in patients with moderately impaired cognitive function; however, these become less evident in the advanced stages of dementia, most likely because of the deteriorating physical and neurological condition of the patient (Tariot and Blazina, 1994). The occurrence of most BPSD, in fact, tends to peak before the advanced stages of dementia.

Also, some BPSD are more persistent than others. For example, a recent study has shown that wandering and agitation are the most enduring behavioral symptoms in patients with AD over a 2-year observation period (Devenand et al., in press).

### **Variation with type of dementia**

More than 70 conditions cause dementia in the elderly (Cohen et al., 1993). By far the most common is Alzheimer's disease (AD) (>50%), followed by vascular dementia (15 - 20%). Cases of combined AD and vascular dementia (VaD) account for about 20%. The prevalence of Lewy body dementia has been estimated to be as high as 20% (Perry, 1990; Jellinger, 1996; Barker et al, 2002), and this figure may be even higher if AD with Parkinsonian features is included. Relative prevalences add up to more than 100% because of discrepancies between studies.

Some studies have found few differences between the prevalences of BPSD in AD and VaD (Cohen et al., 1993; Tariot and Blazina, 1994), others have reported a higher rate of delusions in AD and a higher rate of depression in VaD (Lyketsos et al., 2000). In the study by Cohen, et al (1993), patients with mixed AD and VaD had highest levels of psychiatric disturbance, all symptom levels were high (30% of all patients showed three or more psychiatric symptoms), symptoms increased with severity of the dementia, and the most frequent symptom was agitation, followed by symptoms of depression, apathy and aberrant behavior.

Visual hallucinations are more commonly found in people with dementia with Lewy bodies than in those with Alzheimer's disease or Parkinson's disease (Ala et al., 1997; Beal and Vonsattel, 1998). These occur in approximately 80% of patients with dementia with Lewy bodies compared with about 20% of Alzheimer's disease patients (McKeith et al., 1992).

Fronto-temporal dementia has been associated with higher incidences of many symptoms (Miller, Darby et al. 1997) including impulsivity (Lindau, Almkvist et al. 1998), compulsive behaviors (Rosso, Roks et al. 2001), hypersexuality (Cummings and Duchon, 1981) and verbal outbursts (Mendez, Perryman et al. 1998). Emergence of artist abilities has been associated with left temporal involvement in fronto-temporal dementia (Miller, Cummings et al. 1998). The anatomic distribution of asymmetric atrophy in fronto-temporal dementia has been correlated with specific BPSD (Snowden, Neary et al. 1996). Troublesome and disruptive behaviors have been reported to occur earlier and to be more frequent in Huntington's chorea and Creutzfeldt-Jakob disease (Cummings and Duchon, 1981).

These distinctions are blurred in cases of mixed etiology, including those patients with combined VaD and a degenerative dementia like Alzheimer's disease. In general, any BPSD can occur in any dementia.

## ***Specific symptomatology: psychological***

### **Delusions**

The frequency of delusions in people with dementia is cited as being between 10% and 73% depending on the study population and the definition of dementia (Wragg and Jeste, 1989). The most common delusions in demented people are persecutory or paranoid (Morris et al., 1990).

Delusions occur in different guises in dementia. Five typical delusions seen in dementia (predominantly dementia of the Alzheimer's type) are documented in the Behavioral Pathologic Rating Scale for Alzheimer's disease (BEHAVE-AD; Reisberg et al., 1989):

1. *People are stealing things*  
The probable psychological explanation for this, the most common delusion in people with dementia, is that patients cannot remember the precise location of common household objects. If the delusion is severe the demented person will believe that others are coming into the home to hide or steal objects.
2. *House is not one's home* –which may also be classified as misidentification (Burns, 1996)  
The main contributory factor to this belief is that the patient no longer remembers or recognizes his/her home. And, those who reside in institutional settings often develop the belief, even after many years, that they need to go home. So fixed is the delusion in some demented elderly, that they can attempt to leave the house to go 'home'. This results in wandering. Of course for many patients who are institutionalized this belief is reality and not delusional.
3. *Spouse (or other caregiver) is an impostor* – can also be classified as misidentification (Burns, 1996) or as Capgras phenomenon or delusion. This is a frequent delusion that, in some instances, can provoke anger or violence towards the perceived impostor. This is extremely upsetting to the spouse or caregiver who is already likely to be distressed by the failure to be recognized.
4. *Abandonment*  
Persons with dementia commonly believe they have been abandoned or institutionalized, or imagine that there is a conspiracy to institutionalize them. Although intellectual function declines as dementia progresses, patients retain some insight into their condition. The individual's awareness of having become a burden may be related to this delusion of abandonment. Importantly, for many residents of nursing homes, abandonment may be the reality and not a delusion.
5. *Infidelity*  
Occasionally, persons with dementia will become convinced that their spouse is unfaithful – sexually or otherwise. This conviction may also extend to other caregivers.

According to an analysis of several studies (Tariot and Blazina, 1994), the most frequent single delusion is that 'people are stealing things,' experienced by 18 - 43% of patients. The 'delusion of abandonment' is also relatively common with estimates of its frequency ranging from 3 - 18% (Tariot and Blazina, 1994). As noted above, the 'delusion of infidelity' is occasional with frequency estimates ranging from 1 - 9% (Tariot and Blazina, 1994).

At least two studies suggest that delusions are a risk factor for physical aggression. A study by Deutsch et al. (1991), found that 43.5% of patients with a diagnosis of probable AD had delusions. The presence of delusions was a significant predictor of physical aggression. More recently, Gilley

et al., (1997) reported that the presence of delusions predicts the occurrence and frequency of physical aggression. In their study, 80% of participants who showed high rates of physical aggression, i.e. more than one episode per month also had delusions.

## Hallucinations

Estimates of the frequency of hallucinations in people with dementia range from 12% to 49% (Swearer, 1994). Visual hallucinations are the most common (occurring in up to 30% of patients with dementia) and these are more common in moderate than in mild or severe dementia (Swearer, 1994). In people with Lewy bodies, reports of frequency have been as high as 80% (McKeith et al., 1992). Patients with dementia may also have auditory hallucinations (present in up to 10%), but other types, such as those of an olfactory or tactile nature, are rare (Swearer, 1994).

One common visual hallucination involves seeing people in the home who are not really there, e.g. phantom boarders, also classed as misidentification syndromes. Sometimes these hallucinations are very upsetting to the person with dementia and require treatment. At other times they are not a source of stress (except possibly for the caregiver) and therefore intervention is not required.

In patients with moderately impaired cognitive function, an association may exist between visual misperceptions and hallucinations. A significant percentage of people with dementias have functional impairments related to visual agnosias (difficulty recognizing faces or objects) and many have problems with contrast sensitivity, especially at low frequencies. In such individuals, the boundaries between light and dark appear blurred, partially explaining the common occurrence of visual hallucinations and misidentifications. Thus, examination of auditory and visual function is an essential part of the assessment of any person with dementia with hallucinations (see box).

To anticipate the presence of, or potential for, visual hallucinations in a person with dementia, it is important to:

- evaluate the visual perceptual functions of each patient
- optimize ambient illumination and enhance visual contrast
- educate caregivers about the visual perceptual impairment experienced by persons with dementia and how it affects activities of daily living.

## Misidentifications

Misidentifications in dementia are examples of disorders of perception (Burns, 1996). Unlike hallucinations (which occur in the absence of an external stimulus), misidentifications are misperceptions of external stimuli and can be defined as misperceptions with an associated belief or elaboration that is held with delusional intensity.

Although misidentifications have been defined in several ways, there are four main types:

- presence of persons in the patient's own house (the 'phantom boarder' syndrome)
- misidentification of the patient's own self (often seen as not recognizing their own mirror reflection)
- misidentification of other persons
- misidentification of events on television (the patient imagines these events are occurring in real three-dimensional space).

The frequency of misidentifications varies from study to study, depending on the definition used and the population studied. In a prospective, longitudinal, clinical-pathologic study of 178 AD patients (Burns, 1996), it was found that:

- 17% of patients believed someone else was in their house
- 4% would talk to themselves in the mirror as if to another person
- 12% believed other people were not who they were
- 6% misidentified people on television and could not appreciate that they were not actually present in the room.

Misidentification where a person with dementia does not recognize his or her partner can be especially distressing for a spouse caregiver. Subsequent potential for aggression in patients can make the symptoms particularly worrisome.

In 1990, Ellis and Young described three forms of delusional misidentification which are described here:

- **Capgras syndrome** sometimes called the syndrome of imposters, involves the delusional belief that persons have been replaced by identical doubles. Capgras syndrome may be a form of hypoidentification and related to a type of reduplicative paramnesia. Some patients with Capgras syndrome reduplicate more than just other people (e.g., houses, pets and objects). Capgras syndrome is associated with loss of the autonomic signs that normally accompany the recognition of familiar faces (Ellis et al., 1997). They propose that Capgras patients interpret the loss of affective response for familiar people in a paranoid suspicious way, and this leads them to the conclusion that the person must be an impostor.
- **Fregoli syndrome** is a type of misidentification where patients become convinced that people are dressing up as others in order to affect or influence them. In many ways, Fregoli syndrome is similar to normal experience. If a non-demented person expects to meet someone, they may briefly misidentify a stranger as that person, although they quickly correct the mistake when inconsistent evidence is noted. A patient with Fregoli syndrome attributes the inconsistent evidence to the effects of the disguise.
- **Intermetamorphosis** describes a situation in which the physical appearance of a person is perceived to correspond with the appearance of someone else.

Many family members and caregivers find their own ways of dealing with misidentifications. It is important to realize that what works with one person may not be appropriate for another, and the chosen approach needs to be worked out carefully with reference to the individual's pre-morbid characteristics. In some cases, humor will be appropriate; in other cases, reassurance or diversionary tactics may be more successful (see Module 5).

### **Diagnostic Criteria for Psychosis of Alzheimer's Disease**

These diagnostic criteria (Jeste and Finkel, 2000) are an attempt to identify single aspects of BPSD to allow more specific therapeutic trials. It is hoped that the rigor in which psychosis in dementia is separated from psychosis in other conditions will allow regulatory agencies approve indications for therapy specifically for Psychosis of Alzheimer's Disease. Current efforts are underway to define psychoses in other dementing illnesses more precisely.

#### **Characteristic symptoms**

Presence of visual or auditory hallucinations, or delusions, or both.

**Primary diagnosis**

All the criteria for dementia of the Alzheimer type are met. \*

**Chronology of the onset of symptoms of psychosis vs onset of symptoms of dementia**

There is evidence from the history that the symptoms in Criterion A have not been present continuously since prior to the onset of dementia.

**Duration and severity**

The symptom(s) in Criterion A have been present, at least intermittently, for 1 month or longer. Symptoms are severe enough to cause some disruption in patients' and/or others' functioning.

**Exclusion of schizophrenia and related psychotic disorders**

Criteria for schizophrenia, schizoaffective disorder, delusional disorder or mood disorder with psychotic features have never been met.

**Relationship to delirium**

The disturbance does not occur exclusively during the course of a delirium.

**Exclusion of other causes of psychotic symptoms**

The disturbance is not better accounted for by another general medical condition or direct physiological effects of a substance (e.g. a drug of abuse, a medication).

\*For other dementias, such as vascular dementia, Criterion B will need to be modified appropriately.

**Psychosis of AD Compared With Schizophrenia in the Elderly**

	<b>Psychosis of AD</b>	<b>Schizophrenia</b>
Bizarre or complex delusions	Rare	Frequent
Misidentifications of caregivers	Frequent	Rare
Common form of hallucinations	Visual	Auditory
Schneiderian first-rank symptoms	Rare	Frequent
Active suicidal ideation	Rare	Frequent
Past history of psychosis	Rare	Frequent
Eventual remission of psychosis	Frequent	Uncommon
Need for long-term treatment with antipsychotics	Uncommon	Very common
Mean optimal daily dose of antipsychotics	15–25% of that in a young adult with schizophrenia	40–60% of that in a young adult with schizophrenia

Jeste, D. V. and S. I. Finkel (2000).

**Depression**

Depressive symptoms affect a sizable minority of dementia patients at some time during the course of their dementia. Most studies have been of patients with AD and show depressed mood to occur most frequently, in 40–50% of patients, and, a major depressive disorder being less common, 10–

20% (Wragg and Jeste, 1989). There is often discordance between self-reported symptoms of depression and the observations of collateral sources (Burke et al., 1998). A five-year longitudinal study of patients with AD showed recurrence rates of 85% for depressive symptoms over one year (Levy et al., 1996). A premorbid history of depression increases the chance of depression developing with AD (Harwood, et al., 1999).

Diagnosing depression can be difficult, particularly in patients with moderate and severe dementia. In early dementia, depressed mood and symptoms can usually be elicited according to DSM-IV criteria during a patient interview. As the dementia progresses, diagnosis of depression becomes more difficult because of the increasing language and communication difficulties, and because apathy, weight loss, sleep disturbance and agitation can occur as part of the dementing illness. Depressive disorder should therefore be considered when one or more of the following conditions are noted:

- a pervasive depressed mood and loss of pleasure
- self-deprecatory statements and expressed wishes to die
- a family or personal history of depression prior to the onset of dementia.

Consensus diagnostic criteria for depression in Alzheimer's disease have been proposed (Olin et al., 2002).

## **Apathy**

Apathy and related symptoms are among the most common of the BPSD (Lyketsos, Steinberg et al. 2000). Apathy is present in up to 50% of patients in the early and intermediate stages of AD and other dementias. Patients who are apathetic show a lack of interest in daily activities and personal care and a decrease in different types of interaction:

- social interaction
- facial expression
- vocal inflection
- emotional responsiveness
- initiative

The symptoms of apathy may be mistaken for those of major depression. Both apathy and depression can manifest as diminished interest, psychomotor retardation and lack of energy and insight. Although lack of motivation occurs in apathy and depression, the syndrome of apathy denotes lack of motivation without the dysphoria or vegetative symptoms of depression. The clinician must distinguish a patient who is apathetic from one who is depressed, since the management of each disorder differs. For example, on a pharmacological basis, a patient with depression may require antidepressant medication, while another with apathy may benefit from a cholinesterase inhibitor.

## **Anxiety**

Anxiety in dementia may be related to the manifestation of other BPSD or occur independently. Patients with anxiety and dementia will express previously nonmanifest concerns about their finances, future and health (including their memory) and worries about previously nonstressful events and activities like being away from home (Reisberg et al., 1986).

A common manifestation of anxiety in dementia is 'Godot syndrome'. A person with Godot syndrome will repeatedly ask questions about an upcoming event – a behavior which appears to

result from decreased cognitive (specifically memory) abilities and from the inability to channel remaining thinking capacities productively. This can become so incessant and persistent as to create a major burden for the patient's family and caregivers (Reisberg et al., 1986).

Another anxiety symptom characteristic of dementia patients is fear of being left alone (Reisberg et al., 1986). This fear can be considered a phobia since the anxiety is out of proportion to any real danger. This phobia may become apparent as soon as the spouse or other caregiver goes into another room or may be expressed as repeated requests not to be left alone. Patients with AD sometimes develop other phobias, such as fear of crowds, travel, the dark, or activities such as bathing.

## ***Specific symptomatology: behavioral***

### **Wandering**

Wandering is one of the most troublesome of the behavioral problems that commonly accompany dementia, particularly in terms of the burden it places on caregivers. It is a frequent cause of referral to psychiatric services. There are several different types of behavior covered by the term 'wandering' (Hope and Fairburn, 1990):

- checking (repeatedly seeking the whereabouts of the carer or occasionally another person)
- trailing or stalking, (an extreme form of checking – following the caregiver or another person around excessively)
- pottering or rooting (walking around the house or gardening trying ineffectively to carry out tasks [e.g. washing/drying up, cleaning, weeding])
- aimless walking
- night-time walking
- walking directed towards an inappropriate purpose
- excessive activity
- wandering off, needing to be brought back to the house
- repeatedly attempting to leave the house

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■ Underlying these different types of behavior there may be different 'components' such as hyperactivity or a faulty navigational ability.

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The reported prevalence of wandering varies considerably depending on the population studies; percentages as low as 3% and as high as 53% have been reported (Colenda, 1995).

### **Agitation**

Agitation is defined as inappropriate verbal, vocal or motor activity that is not judged by an outside observer to result directly from the needs or confusion of the person (Cohen-Mansfield and Billig, 1986). Several specific scales, mostly used as research tools, have been developed to define and assess agitated behaviors. One such scale that is now also used in a clinical setting is the Cohen-Mansfield Agitation Inventory (CMAI; Cohen-Mansfield et al., 1989). Agitation in dementia is a complex phenomenon and four subtypes have been identified using the CMAI. The subtypes are listed in Table 2.

**Table 2. Subtypes of agitation.**

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<b>Physically non-aggressive behaviors</b> <ul style="list-style-type: none"><li>● General restlessness</li><li>● Repetitive mannerisms</li><li>● Pacing</li><li>● Trying to get to a different place</li><li>● Handling things inappropriately</li><li>● Hiding things</li><li>● Inappropriate dressing or undressing</li><li>● Repetitive sentences</li></ul>	<b>Verbally non-aggressive behaviors</b> <ul style="list-style-type: none"><li>● Negativism</li><li>● Does not like anything</li><li>● Constant requests for attention</li><li>● Verbal bossiness</li><li>● Complaining or whining</li><li>● Relevant interruptions</li><li>● Irrelevant interruptions</li></ul>
<b>Physically aggressive behaviors</b> <ul style="list-style-type: none"><li>● Hitting</li><li>● Pushing</li><li>● Scratching</li><li>● Grabbing things</li><li>● Grabbing people</li><li>● Kicking and biting</li></ul>	<b>Verbally aggressive behaviors</b> <ul style="list-style-type: none"><li>● Screaming</li><li>● Cursing</li><li>● Temper outbursts</li><li>● Making strange noises</li></ul>

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Studies of dementia patients in nursing homes and adult day care centers have identified the types of patients in which each agitation subtype is likely to occur (Cohen-Mansfield, 1996):

- Physical and verbal aggressions are more likely to occur in patients with dementia who have poor social relationships.
- Physical aggression is typical of patients with severe cognitive impairment and is more common in men.
- Verbal aggression is related to depression and health problems.
- Physically non-aggressive behaviors are seen in patients with moderate to high levels of functional impairment
- Verbally non-aggressive behaviors are more likely to be observed in women with dementia and depression, who are in poor health and may be in chronic pain. These patients have minimal to moderate cognitive impairment and poor social relationships.

Although there is clearly a relationship between subtypes of agitation and the degree of cognitive impairment, dementia per se does not fully explain agitation. Medical, psychological, and environmental factors and premorbid personality have consistently been shown to affect agitation.

Most agitated behaviors signal discomfort and discontent. At least one study has shown that in institutionalized elderly persons with dementia, agitation is a risk factor for falling (Marx et al., 1990). It is important to note, however, that not all agitated behaviors require medical intervention. The reasons for the agitation must be identified in order that appropriate social, environmental, behavioral or medical intervention can be made to alleviate the symptom (see Modules 4, 5, 6).

### **Catastrophic reactions**

Catastrophic reactions, sometimes referred to as rage reactions, are characterized by an excessive and sudden emotional response or physical behavior.

Catastrophic reactions present in one or more of the following ways:

- sudden angry outbursts
- verbal aggression (e.g., shouting and cursing)
- threats of physical aggression
- physical aggression (e.g., hitting, kicking, and biting).

In one study of 90 mildly to moderately impaired patients with AD, caregivers reported sudden angry outbursts in 38% of the patients (Haupt, 1996). This agrees with findings in other investigations. In addition:

- sudden angry outbursts were associated with increased activity and aggressive behavior
- no relationship was found between angry outbursts and depressed appearance, apathy, or anxiety
- aggressive behavior (by patients) contributed most to the relationship between noncognitive symptoms and sudden angry outbursts
- catastrophic reactions could be precipitated by cognitive and noncognitive symptoms, such as:
  - misperception
  - hallucinations
  - delusions.

Delirium, occult pain, infection and certain medications can also provoke catastrophic reactions.

The pathogenic mechanisms for catastrophic reactions are summarized in Table 3.

**Table 3. Pathogenic mechanisms of catastrophic reactions. Reprinted with permission from Haupt, 1996.**

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**Organic variables**

Brain damage (corpora amygdala, temporal lobes, hypothalamus)  
Neurotransmitter dysfunction (decreased serotonin levels in the brain)

**Psychological variables**

Encountering a new environment  
Realization that one is forgetful or ill  
Reduced ability to communicate  
Acting out psychotic distress  
Accentuation of premorbid personality traits  
Problematic relationship to caregiver in the past (troubled dyad)

**Environmental variables**

Unidentified noise  
Inadequate lighting  
Moving to unfamiliar places  
Adversarial patient management style

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**Complaining**

Patients with dementia may complain repeatedly and even be accusatory. Caregivers can feel hurt or angry if they hear statements like, “You stole my things,” “You are mean to me.” or “I want to go home.” Of equal concern is a patient’s inability to complain, for example, about painful conditions.

Caregivers who take a patient’s criticisms personally can provoke pointless arguments, which may cause the patient to have a catastrophic reaction. To cope with complaints and criticisms, caregivers can express sympathy through statements such as “Life does seem cruel” or, “I know you feel lost.” Alternatively, they can ignore the complaints and insults or make use of distractions to decrease complaining.

## **Disinhibition**

Patients with disinhibition syndrome behave impulsively and inappropriately. They may be easily distracted, emotionally unstable, have poor insight and judgment, and be unable to maintain previous levels of social behavior. Other symptoms associated with disinhibition include:

- crying
- euphoria
- verbal aggression
- physical aggression toward other persons and objects
- self-destructive behavior
- sexual disinhibition
- motor agitation
- intrusiveness
- impulsiveness
- wandering

Disinhibition syndrome not only distresses caregivers, it can also have very serious consequences. Expressions of disinhibition such as explosive temper, aggressive outbursts and irritability may incite disagreements and provoke acts of violence. Shoplifting, gambling, impulsive buying and other unrestrained behavior may lead to economic and social problems. Patients who lack judgment may cause motor vehicle accidents or consume excessive alcohol or drugs.

## **Intrusiveness**

Intrusive behavior in patients with dementias can be described as demanding, impatient, clinging or pushing actions that cause the caregiver to do something involuntarily. Intrusive patients push themselves into situations without invitation or encroach on something that is possessed or enjoyed by another.

Intrusiveness has not been well studied and is not included on most behavioral rating scales. However, some scales that are designed to assess behavioral abnormalities in dementia include features related to intrusiveness (e.g., demanding and clinging). Examples of these include:

- Dysfunctional Behavior Rating Instrument (Mungas, 1989)
- Dementia Signs and Symptoms Scale (Loreck, 1994)
- Rating Scale for Aggressive Behavior (Patel, 1992).

In a study by Molley et al. (1991), using the Dysfunction Behavior Rating Instrument, intrusiveness was reported in 45% of patients (N=184) with AD. Similarly, 41% of patients (n=90) with mild to moderate dementia displayed demanding and impatient behavior and, according to caregiver reports, 67% of the patients clung to the caregiver (Haupt, 1996). This behavior was not related to the severity of cognitive and functional impairment.

## **Negativism**

Negativism can be defined as refusal to cooperate. While there are many potential causes of negativism, sometimes patients simply do not understand what they are being asked to do. Negativism can lead to stubbornness, uncooperative behavior and resistance to care. Resistance to care is a troublesome behavior that occurs most commonly in patients with frontal lobe abnormalities. This behavior typically occurs early

in the course of vascular dementia and later in AD. Establishing a daily routine can be helpful in overcoming a patient's resistance to care.

### ***Delirium: a differential diagnosis from BPSD***

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■ Patients with dementia are at a higher risk for developing delirium. Delirious patients may experience the behavioral and psychological symptoms seen in dementia.

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• altered prosody of speech (slurred, slowed, or rapid)  
tremor Diagnosing delirium in a cognitively intact patient is fairly straightforward, with the sudden onset of global impairment easy to recognize. One simple method for detection of delirium is the Confusion Assessment Method or CAM (Inouye et al, 1990), which requires the clinician to assess the following symptoms:

1. Acute onset and fluctuating course
2. Inattention
3. Disorganized thinking
4. Altered level of consciousness

To satisfy criteria for presumptive diagnosis of delirium, the patient must have symptoms 1 and 2, and *either* symptom 3 *or* symptom 4.

Making this diagnosis in a person whose brain has already been damaged by dementia is often difficult, since the delirium is superimposed on existing disordered thought and confusion. In both dementia and delirium, slowing of electroencephalographic activity is noted (except in delirium resulting from sedative withdrawal), as are altered sleep-wake cycles and diurnal variations.

Despite their similarities, it is usually possible to differentiate between delirium and dementia because delirium usually presents with:

- acute or subacute onset of symptoms
- heightened or reduced attention in a patient with pre-existing dementia, or, prominent fluctuations in symptoms
- visual hallucinations accompanied by agitation.

Other signs of delirium include:

- altered psychomotor activity
- or asterixis.

### **Causes of delirium**

Once delirium is diagnosed, appropriate treatment depends on identifying the cause. There are many causes of delirium. The most common causes are noted here:

- Infection, especially urinary tract
- Medication
- Malnutrition/dehydration
- Metabolic illnesses (e.g., certain renal or hepatic diseases)
- Changes/stress in the patient's environment.

- Surgery

Here are several scenarios that illustrate the causes of delirium:

- Patients taking drugs metabolized by the P450 system, including common antihypertensive medications and many psychoactive drugs, may be at risk for delirium if they drink grapefruit juice, a potent inhibitor of the P450-III A4 isoenzyme.
- Alternative medications which often have psychoactive and anticholinergic properties can trigger delirium, as can eye drops with b-blocker properties.
- Delirium also may result if a person with dementia unknowingly takes medication prescribed for family members or friends. This can be a particular problem in nursing homes. In the USA, nursing homes are required under the Omnibus Budget Reconciliation Act to allow patients to keep their medications at their bedside.
- Sedative use as well as the consumption of alcohol by a person with dementia can produce delirium, both by itself and as a withdrawal syndrome.
- Among nursing home residents, hypoxia is a frequent cause of delirium. This condition can result from pneumonia, congestive heart failure, sleep apnea or, less commonly, pulmonary embolism.
- Urinary retention and fecal impaction also must be considered as possible causes of delirium in persons with dementia.

To summarize, delirium and dementia are often difficult to distinguish. This is due in large measure to overlapping symptom profiles and etiologies. In addition, dementia and delirium frequently coexist. Nonetheless, it is important to identify delirium because this will often lead to different therapeutic strategies. Treatment of the causes of delirium in demented patients will often lead to significant improvements in BPSD.

## ***Appendix 1. Diagnostic classification of signs and symptoms in patients with dementia: a historical review***

### **DSM-I, II and III**

Both the Diagnostic and Statistical Manual of Mental Disorders (DSM)-I and DSM-II focused on the intellectual aspects of dementia, rather than the specific behavioral features. The DSM-III (American Psychiatric Association, 1980), viewed by many as a substantial advance in diagnostic clarity, was based on the greater detail with which it described different conditions and the use of specific diagnostic criteria.

The DSM-III maintained the superordinate category of 'organic mental disorder' while specifying the following core criteria for dementia:

- memory impairment
- at least one other feature, chosen from impairment of abstract thinking, impaired judgment, other disturbances of higher cortical function and personality change.
- loss of intellectual abilities sufficient to interfere with social or occupational functioning

In DSM-III, 'primary degenerative dementia' was defined as a dementia of insidious onset with a gradually progressive course. The term dementia was not associated with a specific disease course, but was related most often to the pathology of AD. Primary degenerative dementia was said to be either senile onset (>65 years of age) or presenile onset (<65 years of age).

Few overall changes were made in the revision of the DSM-III (DSM-III-R; American Psychiatric Association, 1987). Again, scant attention was paid to the types of symptoms or behaviors often so troubling in managing patients with dementia. Perhaps the only change of note was renaming the condition 'primary degenerative dementia of the Alzheimer type'.

### **The NINCDS-ADRDA**

In 1984, criteria for the clinical diagnosis of AD were published in a report from the National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer's Association (NINCDS-ADRDA; McKhann et al., 1984). These criteria reflected the efforts of many experts, brought together under the auspices of the USA Department of Health and Human Services, to develop rigorous criteria to facilitate research studies.

The NINCDS-ADRDA criteria defined 'probable Alzheimer's disease' as a condition involving two or more areas of cognitive dysfunction, including memory and another cognitive process. According to the NINCDS-ADRDA criteria, patients with AD show:

- progressive deterioration of other cognitive abilities, such as language, motor skills or perception
- impaired activities of daily living with altered patterns of behavior.

The diagnosis required the exclusion of other etiologic disorders, and the course, while generally progressive, could include a time of clinical stability. Associated symptoms included:

- depression
- insomnia
- incontinence
- delusions
- illusions

- hallucinations
- catastrophic verbal, emotional or physical outbursts
- sexual disorders
- weight loss.

Diagnosis was confirmed by the presence of both the characteristic clinical presentation, as defined by 'probable Alzheimer's disease' and histopathologic evidence obtained by either a biopsy or at autopsy.

In contrast to the DSM-III and DSM-III-R, in which a patient could be diagnosed as having progressive degenerative dementia of the Alzheimer type based on declining memory function and personality change, the NINCDS-ADRDA research criteria required multiple cognitive deficits.

## DSM-IV

The DSM-IV (American Psychiatric Association, 1994) abandoned the term organic mental disorder "because it incorrectly implies that 'non-organic' mental disorders do not have a biological basis." The section formerly titled 'organic mental disorders' was divided into three components, all based on the definition of presumed etiologies:

- delirium, dementia and amnesic and other cognitive disorders
- mental disorders resulting from a general medical condition (i.e., a specifically defined systemic or cerebral diagnosis)
- substance-related disorders.

The DSM-IV definition of dementia incorporated the multiple cognitive deficits standard of the NINCDS-ADRDA criteria, including memory impairment and at least one feature from aphasia, apraxia, agnosia or disturbance in executive functioning. In DSM-IV, greater attention was given to describing associated clinical features, such as problems with perception, mood and emotion, behavior and motor function.

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- When the DSM-IV was being compiled a number of U.S. experts strongly recommended including a variety of descriptive categories to denote BPSD of patients with dementia. Ultimately, the decision was made not to include these and instead, the phrase 'with behavioral disturbance' was included as a "specifier" to identify patients requiring additional treatment to manage their challenging clinical problems.
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## The ICD-10 Classification of Mental and Behavioral Disorders: Clinical Descriptions and Diagnostic Guidelines

These guidelines (World Health Organization [WHO], 1992) followed a somewhat different tradition from DSM-IV and continued to combine both clinical features and course in the concept of dementia. Like DSM-IV, ICD-10 emphasized that patients with dementia, particularly those with chronic, progressive disease, have multiple cognitive deficits. ICD-10 did not include a designation to characterize patients with BPSD, although subtypes of dementia (delusional, hallucinatory, depressive and mixed) were described.

## Summary

Although the specifying phrase 'with behavioral disturbance' was added to DSM-IV, it is unclear how this will be used in everyday clinical practice. Neither DSM-IV nor any other diagnostic nomenclature provides a structured approach to identifying the degree or type of neuropsychiatric signs or symptoms present. As such, several questions remain:

- when BPSD are treated effectively, should the diagnosis change?
- does a particular BPSD have prognostic significance?
- are these symptoms or symptom clusters (i.e., possible syndromes) sufficiently stable to warrant specific subtypes or a typology?

Despite the fact that the BPSD have been described in one form or another for over a century, a nosology that guides physicians regarding measurement or classification is still awaited.

## **Appendix 2. Theories behind existing rating scales for BPSD**

Only recently have researchers begun to develop instruments to assess BPSD. Most dementia rating scales are based on empirical observation of patients with dementia or on information from caregivers, but a widely embraced conceptual framework for BPSD is only in early evolution.

### **Sources of information**

Investigators differ in their beliefs about the best source of information for behavioral scales.

Behavioral ratings have been based on four sources of information:

- family caregivers
- professional caregivers
- physicians' observations of persons with dementia
- self-report by person with dementia.

**Family caregivers** are intimately familiar with BPSD and are well positioned to report such data. Scales based on family reports are appropriate for assessing outpatients living at home. However, the results may be biased by caregiver mood, the sophistication of the caregiver as an observer and the educational level of the caregiver. BEHAVE-AD and Neuropsychiatric Inventory (NPI) are examples of caregiver-based instruments.

**Professional caregivers'** reports, and rating scales based on these (e.g., the Nurses' Observation Scale for Inpatient Evaluation (NOSIE), the Ward Daily Behavior Scale and CMAI), are appropriate for assessing institutionalized patients. These are used primarily with nursing staff and have the advantage of being based on information from persons more experienced in the observation of BPSD. To overcome some of the methodological difficulties, researchers have begun using videotapes of institutionalized patients and scoring randomly selected observation periods.

**Physicians' direct observation of patients** has the advantage of using highly skilled observers, which tends to increase the reliability of the results. A disadvantage of scales based on physicians' observations is that they capture only the symptoms observed during a limited observation period. The Neurobehavior Rating Scale (NRS) is an example of a tool of this type.

**Self-reports by patients** are reliable and valid only in the early stages of a dementing illness. Nevertheless, self-reports of mood changes have been used in some studies applying the Geriatric Depression Scale (GDS), a self-rated depression assessment scale.

### **Content of rating scales for BPSD**

The content of rating scales for BPSD reflects differing assumptions about these symptoms in dementia:

- The Cornell Scale for Depression in Dementia and the Columbia University Scale for Psychopathology in Alzheimer's disease (CUSPAD) are examples of scales that assess mood and psychosis, respectively
- The Pittsburgh Agitation Scale and CMAI are examples of scales which assess behavioral changes common in dementia
- Some scales such as BEHAVE-AD and CERAD combine psychological and behavioral symptoms
- Some (the NRS and the Gottfries-Bräne-Steen [GBS] Scale) include cognitive measures as well as BPSD assessments

others include metric and neurologic symptoms as well as the BPSD, for example, the Alzheimer's Disease Assessment Scale (noncognitive portion) (ADAS-noncog) and the Caretaker Obstreperous-Behavior Rating Assessment (COBRA)

- Scales may provide information on individual behaviors only, global behavior or both. BEHAVE-AD, NPI and Behavior Rating Scale for Dementia (BRSD) score individual behaviors. In addition, BEHAVE-AD has a global rating, NPI has a summary score and BRSD has factors scores.

- 
- Comparisons between scales are rare, but one has shown reliability and validity of three scales – CMAI, BEHAVE-AD and CUSPAD. The best instrument to be used in a specific setting depends on the characteristics of the tool and the BPSD to be evaluated.
- 

### **Properties of rating scales for BPSD**

The structure and properties of rating instruments for BPSD vary widely and reflect the beliefs of authors regarding how best to capture data. BPSD may be judged to be present or absent using a checklist approach (e.g., 1 = mild, 2 = moderate, 3 = severe). They also may be rated using an analog scale, with the patient or caregiver choosing a point between two polar extremes that best characterizes the symptom (e.g., between happy and sad).

### **Differential diagnosis**

A few authors have attempted to develop scales that aid in distinguishing among different dementing illnesses. These scales reflect the theoretical position that different dementias manifest as different behavioral alterations. BEHAVE-AD, for example, assesses BPSD considered to be characteristic of AD. NPI has scales for BPSD common to AD, but also includes scales for symptoms characteristic of frontotemporal degenerations and other dementias.

### **Outcome of assessment**

Most rating instruments for BPSD were designed for cross-sectional use to identify specific symptoms. Longitudinal studies are necessary, however, to determine whether BPSD:

- are trait phenomena that characterize a subgroup of patients in whom they occur continuously
- tend to recur
- are state phenomena that are transient and occur more or less randomly in different patients during the course of dementing illness.

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# Behavioral and Psychological Symptoms of Dementia (BPSD) Educational Pack



The BPSD Educational Pack was produced by the International Psychogeriatric Association (IPA) under an educational grant provided by Janssen-Cilag. The opinions expressed in the BPSD Educational Pack are those of the contributing authors and are not to be construed as the opinions or recommendations of the publishers or sponsors. Full prescribing information must be obtained for any of the drugs or procedures discussed herein.

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## MODULE 3: Etiology

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*Etiological factors of BPSD are multifaceted. Biologic and nonbiologic factors contribute to the development of BPSD. The coming years will hopefully integrate these aspects into a model of diagnosis and therapeutic management which combines pharmacological and nonpharmacological strategies as well as involving the caregiver in the therapeutic process. Development of knowledge of etiological factors of BPSD will strengthen the establishment of such an integrative model. ...* 14

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## **Key messages**

- There are multiple etiologies for the behavioral and psychological symptoms of dementia (BPSD).
- Currently, the best model is one that incorporates genetic (receptor polymorphism), neurobiological aspects (neurochemical, neuropathology), psychological aspects (e.g., premorbid personality, response to stress) and social aspects (e.g., environmental change and caregiver factors).
- There has been much research observing neurochemical and neuropathology changes in the brains of demented patients, but only broad correlations of changes to BPSD can be made. Further research is required before definite conclusions linking neurochemical or neuropathological changes to specific symptoms can be drawn.
- Functional neuroimaging studies suggest that BPSD are not random consequences of diffuse brain illness, but are fundamental expressions of regional cerebral pathology.
- Disruptions of circadian rhythms can result in BPSD and lead to agitation during the day and restlessness at night. Furthermore, abnormalities in circadian rhythm may be responsible for 'sundown syndrome'.
- The emergence of BPSD and the need for hospitalization are often associated with antecedent life events characterized by change in social routine and environment.

## **Introduction**

We are in the first stages of understanding the etiologies for the behavioral and psychological symptoms of dementia (BPSD). Currently, the best model incorporates four aspects of BPSD:

- genetic (mainly receptor polymorphism)
- neurobiological (neurochemical, neuropathology)
- psychological (e.g., premorbid personality, response to stress)
- social aspects (e.g., environmental change and caregiver factors).

For a particular symptom (or group of symptoms), the relative input from each causal source can vary. The importance of an interactive causal model is that it has implications for the development of treatment strategies (see Modules 5 and 6).

This module reviews what is known about likely genetic and neurobiological causes of BPSD and discusses the role of psychological and environmental contributors to these symptoms.

### **Genetic abnormalities in dementia- relationship to BPSD**

Recent studies reported a receptor polymorphism of subtypes of the serotonin receptor associated with a higher degree of aggressive and agitated behavior in patients with dementia (Sukonick et al. 2001) and a dopamine receptor related to psychosis in Alzheimer's disease (Sweet et al. 1998). In addition, there is some evidence of an association between a positive family history of psychiatric illness, namely depression, and an increase in the frequency of BPSD occurring for the first time within Alzheimer's disease (Holmes 2000). A recently published case study revealed that within a family with a tau mutation, affected family members showed schizophrenia-like psychosis at symptom onset of a progressive dementia (Bird et al. 1997). Further investigations are needed to

enhance our knowledge about correlations of genetic abnormalities and specific BPSD symptomatology.

### ***Neurotransmitter changes in dementia – relationship to BPSD***

Significant and multiple neurotransmitter changes have been identified in the brains of people afflicted by dementia – whether dementia of the Alzheimer's type, dementia with Lewy bodies, or vascular dementia. Such neurotransmitter changes are assumed to cause neuroendocrine dysfunction in dementia, mainly in the form of over activity in the hypothalamic-pituitary-adrenal (HPA) axis. Neurotransmitters affected in dementia are:

- acetylcholine
- dopamine
- norepinephrine
- serotonin
- glutamate.

Neurotransmitter changes in the brains of people with the most common cause of dementia, Alzheimer's disease (AD), have been most extensively documented and thus much of the following text refers to AD-specific changes.

### ***Dementia-related changes in the cholinergic system***

A person with AD has several deficits:

- severe disturbances of the cholinergic system
- decreased cholineacetyltransferase activity
- decreased number of cell bodies in the nucleus basalis of Meynert.

Disturbed functioning of the cholinergic system can cause memory impairment, confusion and delirium. Thus, cholinergic drugs, such as acetylcholinesterase inhibitors, may benefit cognitive function in patients with AD. Less well studied are the effects of cholinergic drugs on BPSD and reduced levels of awareness or alertness. The cholinergic deficit in Lewy-body (LBD) disease is reported to be three times as severe as in Alzheimer's disease. Therefore, acetylcholinesterase inhibitors may be even more effective in patients with this form of dementia.

Drugs with anticholinergic effects, such as scopolamine and tricyclic antidepressants, may cause delirium in elderly patients, particularly in those with dementia.

Delirium is associated with many BPSD including hallucinations and delusions, sleep fragmentation and psychomotor agitation (see Module 2). In LBD visual hallucinations and delirium are frequently present throughout the disease course.

- 
- The significant decrease in cholinergic activity may result in a relative increase in monoaminergic activities, leading to hypo manic or manic symptoms, and behavior that includes delusions, hallucinations and physical aggression (Folstein, 1997).
- 

### ***Dementia-related changes in the dopamine system***

Levels of the catecholamines dopamine and norepinephrine are decreased in discrete areas of the brains of AD patients. Approximately 25% of patients with AD have parkinsonian symptoms, which

are associated with dopamine deficiencies. Dopamine also plays a role in cognitive function, such as working memory. In addition, aggressive behavior may, like psychosis, be related to the dopaminergic system. Demented patients with aggression improve in behavior when treated with dopamine-blocking agents (Schneider et al.1990).

In patients with AD, concentrations of the dopamine metabolite, homovanillic acid, are significantly reduced only in the caudate nucleus and increased in the cingulate gyrus (see Figure 1). There is a strong correlation between decreased concentrations of homovanillic acid in the caudate nucleus and intellectual impairment; however, it is not yet known whether there is any correlation between changes in the dopamine system and BPSD.

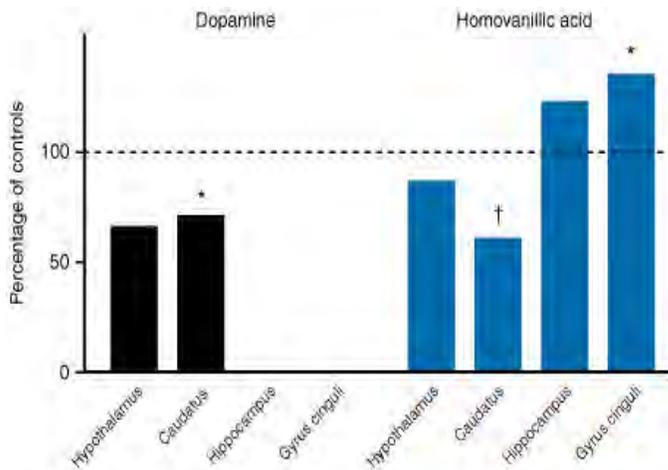


Figure 1. Concentrations of dopamine and homovanillic acid in discrete areas of the brain of patients with dementia of the Alzheimer type. The dotted line is the mean concentration in a control group. \* $p < 0.05$ , † $p < 0.001$ , compared with control group. Adapted with permission from Gottfries et al., 1983.

### ***Dementia-related changes in the norepinephrine system***

Dementia-related changes in the norepinephrine system are complex. Patients with AD show structural defects such as a decreased number of norepinephrine neurons in the locus coeruleus, which leads to reduced norepinephrine levels in brain areas such as the neocortex. Reduced norepinephrine levels are associated with higher rates of depressive symptoms or major depressive disorder in patients with AD.

In contrast, levels of 3-methoxy-4-hydroxy-phenylglycol (MHPG), the metabolite of norepinephrine, are significantly increased in the caudate nucleus, hippocampus and cingulate gyrus in patients with AD, possibly as a compensating mechanism. The high levels of MHPG in the caudate nucleus and hippocampus indicate abnormally high activity in the turnover of norepinephrine. The finding that MHPG levels in the cerebrospinal fluid are not decreased in AD also supports this possibility.

Higher levels of norepinephrine have been found in the substantia nigra of patients with AD and psychotic symptoms than in patients without (Zubenko et al., 1991).

### ***Dementia-related changes in the serotonin system***

Concentrations of serotonin are significantly reduced in several brain areas in patients with AD, although the end metabolite (5-hydroxyindoleacetic acid) is found in normal concentrations. Reduced concentrations of serotonin in the presubiculum have been found in AD patients with psychotic symptoms (Zubenko et al., 1991).

Abnormal functioning of the serotonergic system is implicated in several pathologic disorders. Thus, some of the BPSD may be due to abnormalities in the serotonergic system, which may result in the following:

- depressed mood
- anxiety
- agitation

- restlessness
- aggressiveness

In a controlled study, Nyth and Gottfries (1990) confirmed that some of the mood disturbances seen in demented patients might be due to a deficiency in the serotonergic system. Moderately and severely demented patients with AD were treated with the selective serotonin reuptake inhibitor, citalopram, for 4 weeks. In this study, symptoms such as emotional bluntness, anxiety, fear and panic, depressed mood and restlessness improved with citalopram treatment. Aggressive behavior may also be reduced by treatment with serotonergic agents (Patel and Hope 1993).

### ***Dementia-related changes in glutamate concentrations***

Glutamate is the dominant excitatory neurotransmitter in the brain. It is difficult to say to what extent glutamate concentrations in brain tissue are a marker for metabolism of the glutamate neurotransmitter, but data indicate that patients with AD have fairly severe glutamate loss. The imbalance between the glutamate and dopaminergic systems may lead to dysfunction in the cortical neostriatal-thalamic circuit, which may result in psychotic symptoms.

### ***Neuroendocrine dysfunction in dementia***

In patients with AD, levels of somatostatin, vasopressin, corticotropin-releasing hormone, substance P and neuropeptide Y are significantly reduced in the cortical and sub cortical areas of the brain, whereas levels of the peptide galanin are increased. However, changes in the hypothalamus differ from those in the cortical areas and other sub cortical nuclei. According to some investigators, levels of somatostatin, vasopressin, and neuropeptide Y, as well as those of galanin, are significantly increased in the hypothalamus. The increased concentrations of some neuropeptides might be due to lost inhibitory control over the hypothalamus resulting from failing feedback mechanisms from stress systems. This may lead to more agitation, restlessness, sleep disturbance and other stress-related symptoms.

Results of the dexamethasone depression test in demented patients have shown over-activity in the HPA axis. Between 40% and 60% of patients with dementia have pathologic dexamethasone depression test results: that is, they cannot suppress their cortisol levels when given dexamethasone. Increased release of cortisol in these patients may underlie their disturbed diurnal rhythms and sleep disturbances. Stress-intolerant high cortisol levels also can precipitate confusion.

### ***Neuropathologic changes in dementia – relationship to BPSD***

Despite the clinical importance of BPSD, the pathophysiologic basis for their expression is not yet well understood; however, with improvements in investigative techniques, advances have been made.

### ***Psychotic symptoms***

There is a body of literature, albeit limited, on the relationship between psychotic symptoms in AD and pathology, demonstrated primarily by neuroimaging (see Neuroimaging (structural and functional)) and biochemistry studies.

- 
- In discussing the relationship between regional pathology of the brain and psychotic symptoms, it is important to remember that there is no known persecutory, erotomanic or other delusional center in the brain. Nevertheless, a few generalities can be made.
- 

Delusions are common in extra pyramidal disorders. It also appears that they are associated with calcification of the basal ganglia. They are commonly seen in patients with temporal lobe disorders and more commonly occur in patients with disorders involving the left, rather than the right, side of the brain.

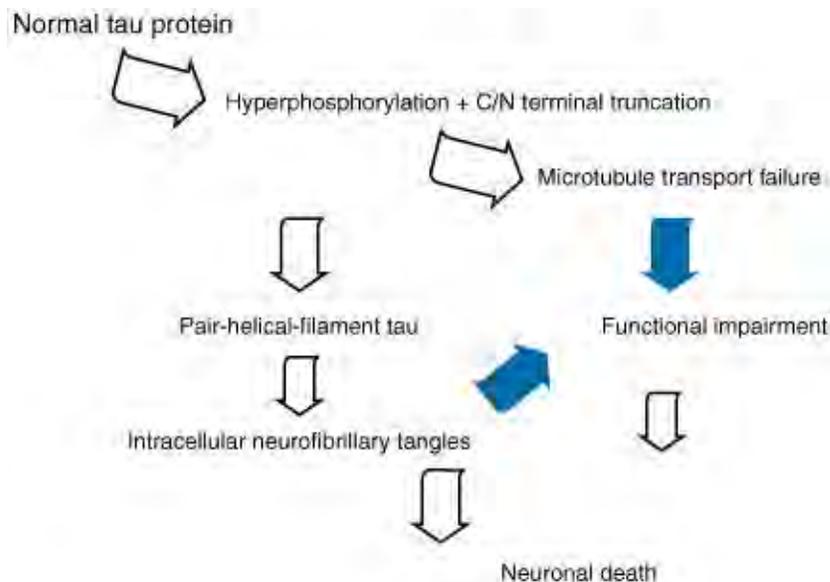
A study by Förstl et al. (1994), examined the relationship between neuropathology and psychotic symptoms in AD patients (23% with hallucinations, 16% with paranoid delusions and 25% with delusional misidentifications).

Compared with controls, AD patients with psychotic symptoms had lower neuronal counts in the following brain regions:

- parahippocampal gyrus
- region CA1 of the hippocampus
- dorsal raphe
- locus ceruleus.

Compared with controls, patients with auditory hallucinations or delusions had higher neuronal counts in the parahippocampal gyrus and lower neuronal counts in the dorsal raphe. Also, delusional misidentification was associated with lower neuronal counts in the CA1 region of the hippocampus.

Histopathologic examination shows that an abnormal protein called paired-helical-filament-tau preferentially accumulates in the neurons of AD patients (Mkaetova-Ladinska et al., 1995), causing the neurons to form tangles and disrupting normal microtubule transport mechanisms (see Figure 2). This process may lead to the production of psychotic symptoms.



*Figure 2. Putative cell biologic mechanism whereby neuronal functional impairment and death result from the formation of abnormal paired-helical-filament-tau protein, which destabilizes microtubules*

*and self-assembles to form paired helical filaments. (Reprinted with permission from Bondareff, 1996).*

Delusions or hallucinations have been found to be related to several abnormalities (Zubenko et al., 1991; Mkaetova-Ladinska et al., 1995):

- higher senile plaque counts in the presubiculum
- higher tangle counts in the frontal cortex
- increased density of extracellular tangles in the parietal lobe
- higher number of neuritic plaques in the occipital cortex.

In addition, delusional misidentification has been found to be related to an increased number of dystrophic neurites in the frontal, parietal and occipital cortices (Mkaetova-Ladinska et al., 1995).

Patients with dementia with Lewy bodies also experience psychotic symptoms and in such patients, levels of acetyltransferase are reduced in the parietal, temporal and occipital cortices and neuronal counts are decreased in the nucleus basalis (Perry et al., 1990).

Aggressive behavior was reported to be associated with neuropathologic lesions in the basal nucleus of Meynert and the locus coeruleus, and with a preservation of neurons in the substantia nigra pars compacta. Apathy and communication failure are related to more severe changes in the hippocampus and the basal nucleus of Meynert (Förstl 2000). More severe neuropathologic changes in the aminergic brain stem nuclei are associated with depressive symptoms in AD patients.

### ***Neuroimaging (structural and functional)***

There is limited evidence from structural neuroimaging studies for relationships between ventricular size (or extent of white matter lesions) and clinical symptoms, including:

- depression
- pathologic affect
- hallucinations
- delusional misidentifications.

Historically noted, Jacoby and Levy (1980) found less severe atrophy in AD patients with delusions than in those without; and Bondareff et al. (1994; 1996), have found smaller ventricle:brain ratios associated with delusions of theft. However, not all studies have supported these findings.

Functional neuroimaging studies suggest that BPSD (in AD at least) are associated with dysfunction in specific brain regions. A series of studies has looked at the relationship between cortical metabolism and BPSD (see box).

#### **Study 1**

An overall association between mean global cortical metabolic rate and total Neurobehavioral Rating Scale (NRS) score was found. There were significant relationships between (Sultzer, 1996):

- agitation/disinhibition factor scores and cortical metabolism in the frontal and temporal lobes
- psychosis factor scores and cortical metabolism in the frontal lobe
- anxiety/depression factor scores and cortical metabolism in the parietal lobe.

**Study 2**

In the brains of patients with AD, a significant association between the severity of delusional thought and reduced metabolic activity was seen specific areas of the brain:

- the anterior cingulate gyrus
- the dorsal and medial aspect of the prefrontal cortex
- the inferior frontal pole.

Preliminary data from the same researchers also suggest that the frontal hypometabolism associated with delusions and behavioral symptoms may normalize after neuroleptic treatment and clinical improvement (Sultzer, 1996).

**Study 3**

In another study of 25 patients with AD (Sultzer, 1996), subjective mood symptoms were greater in patients with low relative parietal metabolism and high relative frontal metabolism whereas, behavioral retardation was greater in those with high parietal metabolism and low frontal metabolism.

**Study 4**

In a SPECT-study with Alzheimer patients suffering from delusions there was a hypoperfusion of the left frontal lobe whereas a hypoperfusion of the parietal lobe was detected in Alzheimer patients with hallucinations (Kotrla et al., 1995).

**Study 5**

Hirono and colleagues (1998) observed a significant correlation between depression and decreased rCMRglc in the bilateral superior frontal and left anterior cingulate cortices of Alzheimer patients.

Other investigators have recently shown relationships between clinical symptoms and cortical function in neurodegenerative conditions. Compared with controls without psychotic symptoms:

- Mentis et al., 1995, reported that metabolism in the orbitofrontal and anterior cingulate regions was lower bilaterally in AD patients with sustained delusions of misidentification
- Starkstein et al., 1994, found that AD patients with delusions had lower bilateral perfusion in the superior and inferior temporal cortex.

Functional neuroimaging correlates of depression have also been explored:

- In patients with Parkinson's disease, Mayberg et al., 1990, showed that the relative glucose metabolic rate in the caudate and orbital-inferior frontal cortex was lower in patients with mild depression compared to those without depression. Improved mood with treatment was also associated with an increase in the orbitofrontal glucose metabolic rate.
- A relationship between depression and frontal dysfunction also has been shown in patients with Huntington's disease (Mayberg et al., 1992).
- Sultzer, 1996, have also shown a relationship between subcortical lesions, depressive symptoms and cortical hypometabolism in patients with vascular dementia who had only subcortical cerebrovascular lesions.

- 
- Taken together, the results of these studies suggest that the BPSD observed are not random consequences of diffuse brain illness, but are fundamental expressions of regional cerebral pathology.
-

An overview of known neurobiologic (neurochemical and neuropathologic) correlates of particular BPSD is given in Table 1.

**Table 1. Neurologic correlates of BPSD (Reproduced with permission from Bolger et al., 1994)**

	<b>Neuropathology</b>	<b>Neurochemistry</b>
Psychosis	↑ plaques in prosubiculum	↓ serotonin in prosubiculum
	↑ tangles in frontal cortex	↑ norepinephrine in substantia nigra
	↓ density in limbic structures	
	↓ density in ocular pathways	
Depression	↓ density in locus coeruleus	↓ norepinephrine in neocortex
	↓ density in substantia nigra	↓ serotonin in all areas
	↓ density in all areas	↑ dopamine in prosubiculum
	↑ ventricle size	↑ monoamine oxidase in all areas
	↓ density in raphe nucleus	↓ somatostatin in spinal fluid
Sleep disturbances	↓ density in brainstem	
Personality changes	↓ density in nucleus basalis of Meynert	↓ acetylcholine in frontal cortex

### ***Circadian rhythms – relationship to BPSD***

Age-related changes in circadian rhythm (e.g., fragmented sleep-wake patterns) occur in many older persons, but are particularly pronounced in patients with AD. Changes in sleep architecture (i.e., reduced rapid eye movement and slow-wave sleep) mean that AD patients are more likely to nap during the day and to be awake at night (Winograd and Jarvik, 1986; Prinz and Viliello, 1993). Patients whose nocturnal restlessness disrupts the sleep of the caregiver are more likely to be institutionalized than those who have cognitive impairment alone.

Disruptions of circadian rhythms can result in BPSD – agitation during the day and restlessness at night. Furthermore, abnormalities in circadian rhythm may be responsible for ‘sundown syndrome’, i.e., the appearance or exacerbation of symptoms of confusion associated with the late afternoon or early evening hours (Evans, 1987).

Recent investigations have shown that Alzheimer patients reveal increased nocturnal activity and a significant phase-delay in their rhythms of core-body temperature and of activity compared with patients with frontotemporal dementia (FTD). The rhythms of FTD patients are highly fragmented and phase-advanced in comparison with controls and apparently uncoupled from the rhythm of core-body temperature (Harper et al. 2001).

### **Biologic correlates of circadian rhythm disturbances**

The degenerative changes in the retina and optic nerve associated with dementia decrease patients' exposure to light, affecting the synchronization of the brain's biologic clock to 24-hour environmental cues. This biologic reduction to light exposure is exacerbated by the environmental reduction in light exposure experienced by patients with dementia: dementia patients (especially those in nursing homes) are more likely to remain inside and thus have less exposure to sunlight.

The suprachiasmatic nucleus, a small structure located on top of the optic chiasm, also known as the biologic clock, is involved in regulating circadian and circannual rhythms. The suprachiasmatic nucleus works by generating biologic rhythms corresponding to an approximately 24-hour period. Normally, in a process called entraining, this endogenous suprachiasmatic nucleus rhythm is synchronized to the 24-hour environmental light-dark cycle. There are now data to show that disturbances of circadian rhythms in dementia are related to changes in the suprachiasmatic nucleus, such as a substantial decrease in the number of vasopressin-expressing neurons.

### ***Personality/psychological contributors to BPSD***

Self-psychology adds another dimension to understanding the psychological reactions that occur in patients with dementia and can impact on BPSD. A conceptual framework for the development of the self is outlined in Figure 3.

Little attention has been paid to regression in the self-sector of personality experienced by patients with dementia, yet the essence of the patient's identity – or self-esteem – is eroded and devastated by this illness. Regression in the self-sector may be caused by a combination of neurological deterioration and concomitant psychological reactions to the dissolution of the self and may result in depressive or psychotic symptoms. However, results are mixed about whether an individual's premorbid personality has a role in the development of BPSD. Patients who have shown suspicious, aggressive or controlling behaviors prior to the onset of dementia are more likely to subsequently develop BPSD.

Recent studies reported that a high level of neuroticism in Alzheimer patients might be associated with a higher risk of BPSD. One study found that a low level of premorbid neuroticism was linked to depressive signs and symptoms, whereas, troublesome behavior was associated with a higher level of premorbid neuroticism (Meins et al., 1998). A further study found no meaningful relationship between premorbid personality and subsequent BPSD, and concluded that biological and environmental factors appear more important (Low et al, 2002).

Investigations into the psychology of the self have led to new ways of understanding a demented patient's attempts to maintain some semblance of self-esteem and identity following progressive cognitive decline (see Module 5). An appreciation of these aids in the understanding of behaviors that may manifest as BPSD.

### ***Environmental and social contributors to BPSD***

Patients with dementia are sensitive to change in their social environment. The emergence of BPSD and the need for hospitalization are often associated with previous life events characterized by

change in social routine and environment (Eriksson, 2000). Relocation can increase depressive behavior and mortality in patients with dementia, as well as agitation, with many patients showing significant disturbed behavior and disorientation for 3 months after a move (Anthony et al., 1987). The greatest effects of relocation on mortality are observed among patients with moderate cognitive impairment.

Stressful life events trigger depression and excess psychiatric morbidity in both the cognitively intact and people with dementia. Cognitively impaired people are often more susceptible to the effects of stressful life events. Therefore, clinical strategies that minimize or buffer the effects of social or environmental change might prevent deterioration in, or development of, BPSD. However, a well-weighted balance of daily activity is an important component of therapeutic interventions to avoid under- and over stimulation.

Most demented patients are advanced in age. They do not only suffer from the dementing illness; they also present with other somatic diseases or are susceptible to develop somatic disturbances. Somatic diseases are a crucial factor for BPSD. They may trigger these symptoms or they may contribute to their presence over time. The following disturbances play a major role: cardiovascular disease, urinary tract and other infections, pain syndromes or somatic symptoms due to pharmacologically mediated adverse events.

Environmental change and stressful events may increase HPA axis activity, thereby causing depression and further exacerbating cognitive deterioration through hippocampal neuron fallout. Alternatively, abnormalities in the HPA axis that occur as part of the degenerative process in AD may actually cause the increased agitation and depression seen in patients with this disease.

Environmental improvement with increased stimulation can also change the neurotransmitter milieu, with increases in cerebrospinal fluid levels of somatostatin and homovanillic acid paralleling an improvement in BPSD. Thus, environmental and behavioral changes appear to be related and this association is reflected by changes in the underlying neurobiology (Lawlor, 1996).

## Caregiver factors

Caregiver distress and poor interpersonal interactions between the patient and caregiver can exacerbate BPSD. For example, when excessive demands are placed on a patient, catastrophic reactions may occur. When the patient and caregiver have had a poor premorbid relationship, the caregiver may misinterpret agitated behavior as purposefully provocative and worsen the situation with an angry retort.

Similarly, patients with dementia and agitation have diverse reactions to caregiver intrusion into their personal space. In a study of 24 nursing home residents with agitation and severe cognitive impairment, touch was related to an increase in aggression but a decrease in physically non-aggressive behaviors (Marx and Werner, 1989). The positive relationship between aggression and touching suggests that touching may be interpreted as a violation of personal space by some patients with dementia. Conversely, for others, touching may act as a quieting and comforting form of communication, as shown by the decrease in strange movements seen in this study. These findings highlight the need to educate caregivers (especially professional caregivers working in residential units) as to the likely diverse reactions of different individuals to such simple interventions as touch (see Module 5).

Recent studies focusing on psychotherapeutic intervention for caregivers have convincingly demonstrated that a modification of problematic behavior among caregivers may alleviate, or even obviate, the occurrence of BPSD in dementia patients (Ballard et al., 2000, Haupt et al., 2000).

For instance, in a 3-month, expert-based group intervention with caregiving relatives of demented patients, agitation and anxiety occurring in familiar surroundings were significantly improved in these patients (Haupt et al., 2000).

## **Conclusion**

Etiological factors of BPSD are multifaceted. Biologic and nonbiologic factors contribute to the development of BPSD. The coming years will hopefully integrate these aspects into a model of diagnosis and therapeutic management which combines pharmacological and nonpharmacological strategies as well as involving the caregiver in the therapeutic process. Development of knowledge of etiological factors of BPSD will strengthen the establishment of such an integrative model.

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# Behavioral and Psychological Symptoms of Dementia (BPSD) Educational Pack



The BPSD Educational Pack was produced by the International Psychogeriatric Association (IPA) under an educational grant provided by Janssen-Cilag. The opinions expressed in the BPSD Educational Pack are those of the contributing authors and are not to be construed as the opinions or recommendations of the publishers or sponsors. Full prescribing information must be obtained for any of the drugs or procedures discussed herein.

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## MODULE 4: Role of caregivers

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## ***Key messages***

- Support by caring relatives is a key factor in community care of people with dementia.
- The emotional relationship between the responsible relative and the older patient significantly determines whether family care can be maintained.
- An effective care system enables caregivers to continue caring for their demented relatives at home and, at the same time, minimizes the negative consequences to them.
- The demands of caregiving may not precipitate an illness event per se in the caregiver, but rather, may aggravate existing vulnerabilities to illness.
- Enhancing the skill of the caregiver in interacting with the patient may prolong the caregiver's ability to provide in-home care and improve the quality of life of both.
- Consideration of BPSD, without understanding the context for the behaviors, can cause staff to view the person with dementia as a collection of symptoms rather than as a whole person.
- Caregiver distress and poor interpersonal relations between the patient and the caregiver can exacerbate BPSD.
- Caregivers can provide useful information about antecedents of, and possible reasons for behavioral problems. This information usually requires more than a single, brief interview.
- Caregivers who have had a poor premorbid relationship with patients are more likely to misinterpret agitated behavior as purposefully provocative and worsen the situation with an angry retort.

## ***Introduction***

Support by caring relatives is the key to continuing community care of people with dementia. Community care is a valid recognition of the right of people with dementia to live as independently as possible in familiar surroundings, such as at home. But often, family care is not possible or sustainable for a number of reasons. Research studies have identified factors that affect the well being of caregivers. For example, the emotional relationship between the responsible relative and the person with dementia significantly determines whether family care can be maintained. Troublesome behavioral and psychological symptoms of dementia (BPSD), and the burden that they create for the family caregiver, are key factors in precipitating a move from family care to a nursing home or other residential care. Also, BPSD can impose a 'caregiver burden' on professionals involved in the care of dementia patients.

Fortunately, there are strategies that have been shown, both clinically and in research, to reduce the burden that caregivers experience in looking after a person with dementia. This module discusses the impact of BPSD on the psychological and physical health of the family and professional caregiver (i.e., their contribution to caregiver burden) and offers some suggestions for interventions shown to reduce that burden.

## ***What is caregiver burden?***

To define 'caregiver burden' more clearly, some researchers use the concepts of objective and subjective burden (Montgomery et al., 1985):

- objective burden refers to the practical problems associated with caregiving such as continuous nursing care
- subjective burden, also called strain, refers to the emotional reaction of the caregiver (e.g., reduced morale, anxiety and depression).

### ***Factors associated with caregiver burden***

BPSD rather than cognitive dysfunction per se or physical dependence/functional impairment impose the greatest burden on caregivers. These include:

- screaming
- physical aggression
- personality clashes (arguments between patients and caregivers)
- wandering
- depression
- resistance to help with activities of daily living (dressing, washing, toileting, eating)
- suspiciousness, accusations
- not sleeping at night.

The above symptoms are recognized as the most burdensome and the most common reasons for psychiatric referral and premature institutionalization.

Although BPSD themselves are clearly the major contributor to caregiver burden, the reaction of the caregiver to BPSD is also important. Caregivers differ in their responses to BPSD and vary in their skills to manage them – not all caregivers find the same symptoms to be troublesome. A number of research studies and clinical observations have identified caregiver characteristics that are either predictive of, or alleviate, burden (Gilleard et al., 1984; Zarit et al., 1986; Morris et al., 1988; Brodaty and Hadzi-Pavlovic, 1990; Vitaliano et al., 1991) (see boxes below and Figure 1).

### **Predictors of Burden**

#### **Very important in predicting caregiver burden**

- Delusions, hallucinations and depression
- Disruptive behaviors (e.g. physical aggression)

#### **Somewhat important in predicting caregiver burden**

- Male gender (though not independently of BPSD, which occur in a higher proportion of men than women)
- Younger age of patient

#### **Doubtful or not important in predicting caregiver burden**

- Type of dementia
- Severity of dementia (i.e., level of cognitive impairment, need for supervision and assistance)
- Cognitive status
- Functional status (ability to work and live independently, manage simple chores and care for self)
- Duration of dementia

### **Predictors of burden: caregiver characteristics**

- Care providers experience greater burden than care managers
- Spouses > relatives
- Women > men
- Proximity (caregivers in closest contact; cohabiting caregivers are under most stress)
- Immature coping mechanisms
- Less support from family and friends
- Less knowledge about dementia, its effects and management
- Poor premorbid relationship with dementia person
- High levels of negative expressed emotions, notably hostility and criticism

### **Protective factors: caregiver characteristics**

- Informal supports (e.g., caring family, friends, neighbors)
- Knowledge about dementia, its effects and management
- Mature coping skills (e.g., problem solving)
- Support groups (e.g., Alzheimer's Association)

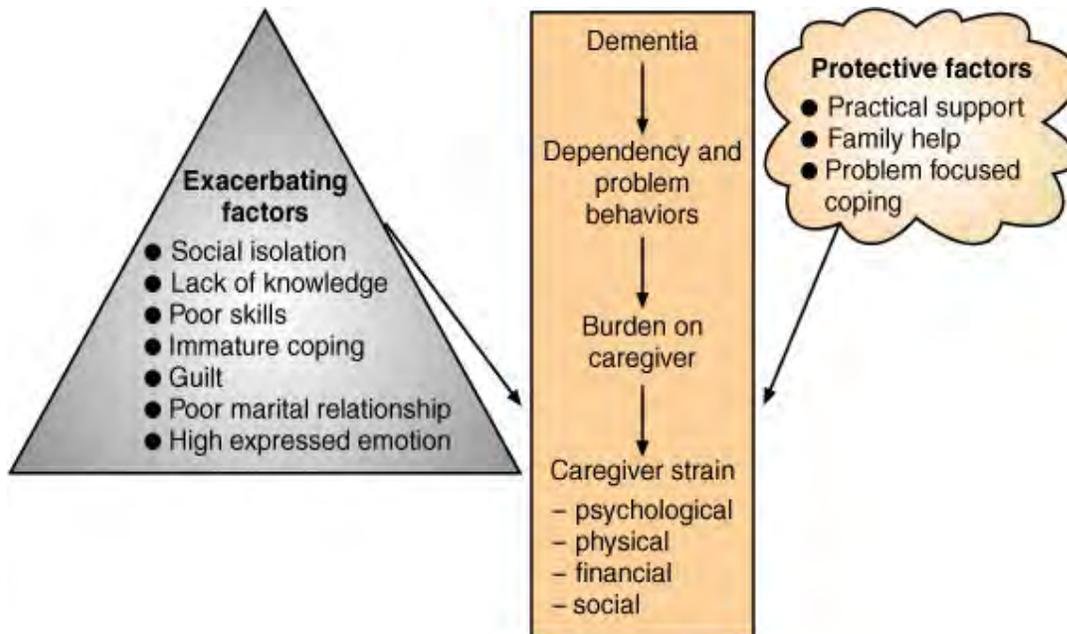


Figure 1. Model of effects of dementia on caregivers. Reprinted with permission from Brodaty, 1996.

## ***The impact of BPSD on family caregivers***

### **Psychological health**

Caregivers are at high risk for developing psychological distress (George and Gwyther, 1986; Whitlatch et al., 1991) and rates of depression and anxiety are increased compared with the general population. The prevalence of depression in adult caregivers of dementia patients has ranged from 14 - 47% in various studies. In addition, 10% of caregivers have been found to meet Diagnostic and Statistical Manual of Mental Disorders Revised Third Edition (DSM-III-R) criteria for anxiety (Dura et al., 1991). Furthermore, researchers report that 7 - 31% of dementia caregivers are taking psychotropic drugs; rates, which are slightly higher than, might be found in the general population (Schulz et al., 1995).

Anger and resentment are emotions commonly felt by caregivers, sometimes bringing the caregiver to the point of violence. In a study of 236 family caregivers of dementia patients, one-fifth experienced violent feelings and feared that they might act on their impulses. Of that one-fifth, one-third reported that they had actually engaged in violent behavior (Pillemer and Sutor, 1992).

Levels of interpersonal and family stress are high in families caring for a demented patient. Among the variables most strongly associated with a caregiver's perception of interpersonal and family stress are behavioral and emotional changes experienced by the patient, changes in the patient's sleep pattern (Schulz et al., 1995) and demanding behaviors (Gilleard et al., 1982; Brodaty and Hadzi-Pavlovic, 1990).

Aneshensel et al. (1995) examined what happens to caregivers as BPSD increase or decrease over time. BPSD were associated with greater caregiver depression when they resulted in:

- an increase in subjective burden

- a feeling of being trapped or confined in the caregiving role.

### **Physical health**

Caregiving has an effect on physical health. Studies have now reported:

- compromised immune function among caregivers (Kiecolt-Glaser, et al, 1987; );
- increased systolic blood pressure among men caring for persons with dementia (Schulz R, Vistainer P, Williamson GM. 1990. Psychiatric and physical morbidity effects of caregiving. J Gerontol; 45:P181-P191).

There is also some evidence linking caregiving to detrimental health-related behaviors such as inadequate sleep and rest, or not seeing a doctor when necessary.

An important emerging area of research evaluating health outcomes in caregivers focuses on changes in subclinical disease as indicators of health effects:

- hypertension
- pulmonary function
- blood chemistries
- cardiac arrhythmia
- Insulin glucose levels
- progression of cardiovascular disease.

- 
- Although demands of caregiving may not precipitate an illness event per se, they may aggravate existing vulnerabilities.
- 

It is likely that the prolonged distress, inherent in caring for a spouse with dementia, may combine with genetic vulnerabilities and current disease status leading to more serious pathophysiology, particularly when both the disease condition and the stressor have been present for several years.

### ***The impact of family caregivers on BPSD***

The behavior of the caregiver towards the person with BPSD has a direct and significant impact on the patient. While the negative effects of BPSD on the caregiver are well documented, there is little appreciation of the caregiver's ability to influence the occurrence and severity of BPSD (see box below). For example, many caregivers believe that the BPSD exhibited by the patient are under that person's control and so must represent antagonistic feelings to the caregiver. Such caregivers experience the patient's forgetfulness as irresponsibility, irascibility as a lack of appreciation, and repetitive questioning as a deliberate attempt to annoy, and are likely to express criticism or hostility towards the patient, which may well further distress the patient. Enhancing the skill of the caregiver in interacting with the patient may prolong the caregiver's ability to provide in-home care and enhance the quality of life of both parties.

#### Caregiver behaviors that can exacerbate BPSD

- Creating sudden and unexpected changes in a patient's routine or environment
- Instigating 'power struggles' with the patient: for example, insisting that a patient do something a certain way or wear a particular article of clothing
- Placing demands on the patient that exceed his or her capabilities

- Being excessively critical of the patient
- Ignoring the patient's needs
- Being excessively rigid or controlling
- Repeatedly prompting or questioning to 'make' the patient remember something
- Being angry or aggressive towards the patient
- Becoming exasperated

- 
- Adverse caregiver behaviors have the potential to incite a 'catastrophic reaction' when the patient exhibiting BPSD is unable to deal with the unexpected stress.
- 

**Caregiver characteristics that alleviate the occurrence and impact of BPSD**

- An empathic, patient, kind, caring, 'warm' attitude toward the patient
- Efforts to understand the causality and meaning behind the behavior
- Unhurried, patient attitude
- Flexible personality, enabling the caregiver not to insist rigidly on compliance
- Adaptability and ability to accept change
- Maintenance of realistic expectations of the patient's abilities
- Reasonable degree of tolerance for 'problem' behaviors such as repetitive activities
- Commitment to keep the patient involved in day-to-day activities
- Fostering of a sense of individualism in the patient
- Allowing the patient at least a perception of control over his or her life and environment
- Sense of genuine concern for the patient's well-being and best interests
- Respect for the patient as a person with emotions and feelings
- Absence of a feeling of shame over a loved one's illness
- Lack of desire to 'hide' the disease from others
- Maintenance of a sense of humor
- Absence of thoughts dwelling on the patient's limitations
- Development and maintenance of an emotional support structure

***Interventions for the caregiver to reduce caregiver burden***

The relief of caregiver burden may considerably decrease BPSD in persons with dementia and there is a range of caregiver interventions designed to do just that. Caregiver interventions can be targeted at three broad areas: psychological support, educational activity and development of a social support system for the caregiver. Specific elements within these broad categories are listed in Table 1.

**Table 1. Elements of caregiver interventions.** Reprinted with permission from Brodaty, 1992, (adapted from Toseland and Rossiter, 1989).

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**Psychological**

- Support
  - ventilation (talking about feelings; unburdening)
  - group process/sharing/universality (feeling part of a group and changing the perception from "I thought I was alone, the only one in the world going through this" to "I know that I am someone with a role. I am a caregiver")
  - learning (through didactic teaching by examples from others in similar positions)

- mutual support (emotional or practical support caregivers provide each other [e.g., mutual minding of dependents])
- Counseling/insight therapy/cognitive therapy/relaxation training/stress management (develop effective means of dealing with stress to relieve anxiety, depression and other negative effects)
- Emotional impact – stress, anger, grief, guilt
  - by talking about their feelings, caregivers realize that they are not the monsters they imagine themselves to be for harboring such thoughts and that their feelings can be a reaction to the primitive, infantile behaviors of the person with dementia
- Self-care (caregivers are better able to look after the demented patient and more capable of managing BPSD if they are well, both physically and psychologically)
- Interpersonal relations and communication
  - the means to managing dementia and BPSD are as important as the ends; how caregivers communicate in attempting to change a behavior can determine how successful they will be

### **Educational**

- Information (e.g., progression of the illness)
- Improving home care skills
- Developing therapeutic skills, problem-solving, behavioral techniques
- Planning – emergencies, legal, financial

### **Developing support system**

- Personal, family
- Community
- Professional e.g.,
  - a social worker able to listen to and counsel a caregiver
  - a nurse able to help with administering medication
  - an occupational therapist to help plan activities and organize the house
  - a care assistant able to help with dressing/washing the person with dementia
  - professional respite care

- 
- A detailed assessment of the caregiver is a necessary first step in reducing caregiver burden because a symptom or behavior that is stressful for one caregiver may not be stressful for another.
- 

It is important to help the caregiver control a situation that is stressful, but not to intervene when it is manageable. There are data to show that comprehensive counseling for caregivers and extended families (Mittelman et al, 1994,1995), and caregiver programs (Brodaty and Gresham, 1989, Brodaty et al, 1997) can both reduce caregiver distress and delay institutionalization.

The comprehensive caregiver training programs were multi-faceted:

- Psychological – relieving caregiver distress, allowing ventilation, dealing with guilt, encouraging more reliance on others, discouraging martyrdom
- Didactic – teaching the caregiver about dementia, BPSD, medications, management skills (i.e., how to cope with BPSD, how to communicate with a person with dementia)
- Physical relief - encouraging the caregivers to separate from the person with dementia by actually sending them on excursions while providing respite care
- Social welfare - informing them about social services and social benefit entitlements, organization in the home, exercise, diet and medico-legal matters.

For 12 months after the intensive 10-day training program (Brodaty and Gresham, 1989), caregivers received booster sessions by way of telephone conference calls. At the time of the exit interview, it was evident that different aspects of the program were most helpful for different caregivers and no one aspect was critical for all (Brodaty et al, 1997).

A meta-analysis of caregiver interventions concluded that they were of at least modest efficacy in reducing psychological morbidity in caregivers and moderate efficacy in enhancing caregiver knowledge. Success was more likely when the intervention included the patient as well as the caregiver. Short educational interventions were not successful and marital (dyadic) counseling appeared to be harmful to caregivers (Brodaty et al, in press). Early results from a combined drug treatment for AD and counseling for caregivers appear encouraging (Mittelman et al, 2001).

### **Provision of information**

Provision of information to family caregivers is a key intervention and one that can be executed relatively easily within a group setting or on an individual basis. Caregivers should be given:

- Information on the illness
- Techniques for dealing with specific BPSD (see Module 5)
- Techniques for ensuring the patient's physical safety and well-being
- Techniques for coping with difficult activities of daily living (such as bathing and dressing)
- Methods for obtaining additional personal assistance, entitlements and respite services (e.g., day care, home care).

### **Use of family meetings**

Family counseling has been shown to be effective in relieving caregiver burden (Whitlatch et al., 1991; Mittelman et al., 1994; 1995). The meetings with families are different from the typical case conference and were developed based on the premise that working directly with the whole family might be an effective way to increase the support available to the primary caregiver (Zarit et al., 1985). The primary goal is to facilitate the family's own skills at problem solving and bring these to bear on the situation. A detailed protocol for family meetings is found in Zarit et al. (1985).

### **Use of respite services**

Respite care aims to provide the caregiver with a break from the responsibility and confinement of caring for a dependent with dementia, enabling the caregiver to enjoy some time alone. There are different types of respite, including:

- In-home care - a professional comes into the family home to spend time with the patient with dementia
- Overnight or residential respite - the patient with dementia goes into residential care for a period ranging from one night to several weeks. There is some evidence for the efficacy of residential respite care, and some argue that using residential respite in dedicated facilities in a planned prophylactic manner can enhance this (Brodaty and Gresham, 1992).
- This should enable the caregiver to manage longer with less psychological distress. There is also some evidence that patients with dementia temporarily exhibit more BPSD after returning home after a period of residential respite. Caregivers require preparation for this occurrence.
- Adult day care - the person with dementia attends a day center, thus providing him or her with stimulation and the caregiver with some free time

- Short inpatient stay - admission of the patient with dementia to a hospital for a procedure, investigation or trial of new medication.

A major evaluation of adult day care for dementia found that adequate amounts of day care (twice a week for at least 3 months) reduced many different stress indicators compared with control subjects not receiving respite care (Zarit et al., 1996; Zarit, 2002). In addition, a meta-analysis of comparable studies of respite care (i.e., similar control groups) found a moderate effect of respite care in relieving caregiver burden and dysphoria (Knight et al., 1993).

Many families wait too long before using respite care. Respite care is best used in a prophylactic manner to prevent caregiver breakdown, rather than as an emergency measure once caregivers can no longer cope.

## **Examples of caregiver programs**

One caregiver program that combines many of the interventions outlined here is run by the Brooklyn Alzheimer's Disease Assistance Center (Magai et al., 1995). This program is designed to address educational and emotional aspects of 'caregiver distress' and takes a six-pronged approach, detailed below.

1. Information and case management  
Much of the initial effort is aimed at teaching caregivers about the stages of the disorder and the behaviors that commonly accompany each stage. It is emphasized that these behaviors are generally not intentional, but reflect underlying brain dysfunction.  
  
Caregivers are given oral, written and audio taped information about AD support services (e.g., respite care, home aides) and entitlements. They are also taught to identify and define carefully the troubling behaviors so that specific strategies can be employed. Once problems are viewed as specific and manageable, caregiver distress usually dissipates.
2. Support groups  
Caregivers are encouraged to attend a weekly support group in which members discuss techniques for handling behavioral problems and emotional concerns of the AD patient.
3. Activity groups  
Caregivers are encouraged to attend a weekly patient activity group to observe and learn techniques and activities for managing behavioral problems.
4. Accessibility to professional assistance  
Caregivers are encouraged to call or meet frequently with social work staff and psychiatrists who can assist with their concerns about the patient's behavior and illness as well as their own distress.
5. Respite services  
Caregivers are encouraged to utilize home support services and to send the patient to a day program. Case managers work closely with the caregiver to link them with these services.
6. Intensive individual, group or family therapy  
For caregivers who are experiencing more persistent and serious emotional difficulties referrals are made for individual or group psychotherapy or family therapy.

In another example from the USA, Mittelman et al. (1994; 1995) demonstrated how an eight-point program of counseling for families consistently reduced the number of emotional complaints (e.g., depression, anger, anxiety and insomnia) from caregivers. The program also effectively delayed the

decision to place a spouse or parent with dementia in a nursing home. By the end of the program, only one of the 41 families who had initially been considering nursing home placement for their demented relative actually needed to do so. The 6-month counseling program included:

- advice and assistance in getting auxiliary help
- support groups
- ensuring that families were aware of community resources
- direct counseling of individual caregivers and family members.

### ***Interventions targeted at the patient with BPSD (mediated by the caregiver)***

Management by the caregiver of BPSD has had promising results with a variety of problems, including:

- agitation
- aggressiveness
- depression.

The solid foundation for any clinical intervention directed at modifying the caregiver's contribution to BPSD is helping caregivers to think about and identify appropriate behavioral treatments, rather than responding in rigidly, predetermined ways to specific problems.

There are two main components of this approach:

1. Viewing behavior in the context of a disease which affects cognitive function.
  - Caregivers often misinterpret common problems. For example, they may erroneously believe that a patient asks the same question over and over again to annoy the caregiver or to get attention or because of laziness. The goal is to help caregivers understand that BPSD have an organic basis.
  - Caregivers are encouraged to think about why someone with a memory-impairing disease is behaving in this way (because the person with dementia actually cannot remember) and how that person must feel about this. While caregivers may not be able to respond effectively to the content of a question such as "When can I see my mother?" it is possible to respond to the underlying emotions (e.g., by providing comfort through reminiscence about the patient's mother).
  - By re-labeling these symptoms, caregivers break the pattern of arguing with patients over factual issues.
  - Caregivers' responses can contribute to BPSD.
2. Problem solving and BPSD.
  - Increasing the caregiver's understanding of BPSD flows naturally into the second step: problem-solving
  - Drawn from contemporary behavior therapy, problem solving consists of a series of steps to identify causes and reinforcement of current problems, and generate and implement possible solutions (see Table 2). As an example, inactivity is frequently followed by agitation, which in turn is reinforced by attention. Once such a pattern is identified, the caregiver and clinician can work together to determine ways in which the sequence can be interrupted. Another answer is to introduce an activity that heads off periods of agitation. A further solution may be to reduce or adjust the level of environmental stimulation to eliminate agitation while providing verbal and/or non-verbal reassurance.

In a controlled study assessing different treatments for depression occurring in persons with Alzheimer's disease, Teri and colleagues (1997) found that family caregivers administering problem-solving techniques or pleasurable events schedules reduced the rates and levels of depression in persons with Alzheimer's disease. As a bonus, the caregivers' own levels of depression were significantly lower.

**Table 2. The problem-solving approach to management of BPSD.**

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- Assessment – describe and note frequency
  - Identify antecedents, describe behaviors and note consequences (A-B-C approach)
  - Generate solutions
  - Select a solution
  - Rehearse the solution
  - Implement and evaluate
- 

The assessment of patients with BPSD is complicated by the fact that patients are usually unable to express reasons for their behavior and feelings. It is very important that caregivers try to understand this and attempt to determine the underlying basis of the target symptom. Furthermore, establishing a baseline of the frequency and severity of the targeted BPSD is a significant step in problem solving. Then, when a pharmacological or non-pharmacological intervention is introduced, continued monitoring of the symptom by the caregiver can provide an accurate evaluation of the effectiveness of treatment. This information will help clinicians decide when an intervention has been helpful or when an alternative strategy should be initiated.

A study by Hinchliffe, et al (1992; 1995) illustrates the importance of a partnership approach between clinicians and family caregivers. In this study, individual care packages were developed for each patient in which the caregiver had a key role. The care package included:

- Twelve hours with a hospital physician specializing in psychiatry
- Medication for the patient
- Day care center respite (adult day care)
- Teaching behavioral techniques to the caregiver (see Module 5)
- Psychological support and, where necessary, medication for the caregiver.

The authors concluded that the intervention led to improvement in the mental health of the caregiver and decreased BPSD. When BPSD persisted, psychological problems, such as depression and anxiety, remained unresolved in caregivers, suggesting that BPSD are of central importance in determining caregiver mental health.

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- The use of behavioral treatment interventions requires training and experience to obtain optimal results. Clinicians without prior training in behavioral methods should seek consultation before using them.
- 

### ***Professional caregivers and BPSD***

It is not only family caregivers who can affect and be affected by BPSD – the reactions of professional staff to BPSD are also relevant in providing good care to patients with dementia. Once again, BPSD can cause staff stress and conversely staff management practices can influence BPSD.

Research into the stress levels experienced by professional caregivers has lagged behind similar inquiries into the experiences of family caregivers. Reports of high levels of stress symptoms in psychogeriatric nursing staff are inconsistent. One study found that work was cited as the main contributory factor to stress levels among nurses (Livingston and Livingston, 1984). Another study (Macpherson et al., 1994) found no relationship between psychological disturbance in staff and demographic or work-related factors. In some studies staff turnover has been higher in work places providing care for people with dementia compared to other geriatric facilities which may be because it is more stressful than general nursing (Åström 1990).

In addition to managing BPSD, health professionals caring for people suffering from dementia face several other major problems. These include:

- High dependence of the person with dementia (e.g., inability to dress or wash oneself and use cutlery, related to a patient's loss of functional abilities)
- Communication difficulties for the person with dementia (e.g., the patient may be unable to understand what is being said [receptive aphasia] or unable to express themselves [expressive aphasia])
- Lack of feedback from the person with dementia on actions which are meant to be in that person's interests (e.g., the caregiver does not know what the patient wants or how the patient is feeling about the caregiver intervention)
- Risk of abuse or of doing things that are experienced as abusive by the person with dementia (e.g., the person with dementia may misinterpret help with undressing as the caregiver trying to steal their clothes and react angrily).

These problems cause staff to feel uncertain about the care they provide. In an interview study by Berg et al (1998), it was found that nurses felt like the patients were completely in their hands and that they determined the life of the patient. The lack of validation of their actions evoked uncertainty.

Progression of dementia is accompanied by continuous loss of functional abilities. This makes the patient increasingly dependent on others to meet their physical needs and forces staff to encroach on the intimate zones or boundaries of the person. If this is perceived as offensive or intrusive, it will have direct relevance to BPSD.

## **Patient reactions to staff interventions**

The fact that people with dementia have impaired cognition does not mean that they are indifferent to what happens to them. They react to staff interventions in various ways:

- positively and with gratitude
- negatively by being hostile and aggressive
- in an uninterpretable way (inability to express feelings coherently).

Patients' reactions are often related to how they interpret the nurses' actions – a person with dementia may interpret an action differently from its purpose. For example, the person with dementia may view the caregiver helping him change into pajamas as someone trying to steal his clothes. Aggressive behaviors often occur during invasions of personal space or personal care.

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- Actions and reactions considered in isolation from the context and the person involved can result in staff withdrawing and viewing the patient from a diagnostic perspective rather than as a person.
- 

There is an active interaction between patients with dementia and the professionals who provide private, personal care from which the patient may recoil. Thus, professionals create the world

surrounding the person with dementia – it can be a world of hostility or anger, or the opposite. When it is hostile, the results for the care staff may be:

- low job satisfaction, guilt, low creativity, more burnout and a poorer quality of care
- task-oriented and impersonal care, poorly adapted to the needs of a person with a life history and likes and dislikes.

### **Absence of reliable communication**

Professional staff receives little, if any, verbal feedback from either the person with dementia or from the family, particularly in the later stages of dementia. Information gleaned from verbal communications may be inconsistent or incorrect. This increases the risk that:

- staff may misinterpret the patient's likes and dislikes
- interventions fail
- staff abandon further attempts to understand the wishes of the patient
- staff interprets a patient's behavior as disturbed or meaningless.

Thus there is a need for a supportive structure to support nurses in their caring.

### **The importance of perspective**

Most research has focused on the person with dementia from an 'outside' perspective (i.e., observing the person with dementia). From a caring perspective, more knowledge is needed from the 'inside', by understanding what it is like for the person. It is important to consider:

- what it means to the patient to be demented
- if there is any associated suffering
- how to interpret communication
- how to interact despite communication difficulties.

Some staff may be intuitive, have experience and know what to do; others often have to resort to trial and error, very much as mothers do with their infants. This kind of interpretative process is fraught with difficulty. A major issue is that, with the increasing loss of verbal and non-verbal communication abilities, the possibility to 'negotiate' between the patient and the professional caregiver on how best to provide care is severely curtailed.

There is always a risk of a vicious cycle developing in the professional care of the person with dementia that is harmful to both the professional and to the patient:

- the person with dementia acts in an uninterpretable or unacceptable manner
- the professional fails to understand why, feels distressed, communicates this non-verbally, but continues regardless with the task
- the patient becomes stressed and reacts with hostility or aggression.

In extreme cases, professionals may abuse patients by using physical force, neglecting them or demanding that they do things that are not in their best interest.

### **Supportive structures for professional caregivers**

Caring for patients manifesting BPSD can be very demanding for professional staff. Supportive structures can assist nurses and other staff to:

- understand the behaviors they encounter better
- help their patients more effectively

- debriefing
- help staff feel more fulfilled in their professional role.

Negative feedback loops (the 'vicious cycle' outlined above) can be turned into positive supportive ones by implementing structures that include a focus on the task-aspect of caring for patients. There are models and instruments for assessing the functional ability of the person with dementia that have been found to be successful in structuring provision of care based upon areas of the impaired person's life. (See Figure 2).

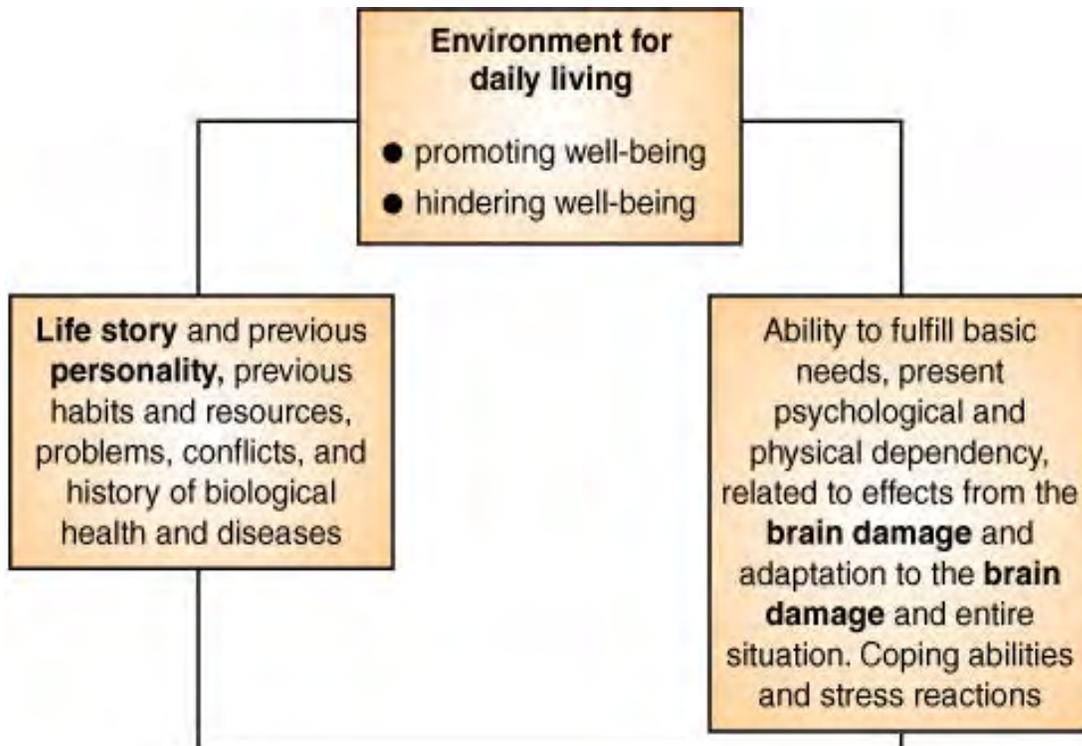


Figure 2. Various aspects of a cognitively impaired person's life that should be covered in the process of needs assessment. Reprinted with permission from Hallberg, 1997.

Proper analysis of BPSD requires knowledge of the affected person's biopsychosocial life history, current situation, the biopsychosocial consequences of brain damage and possible coping strategies.

Regular and repeated reviews are required. Documentation of the provision and outcomes of care procedures is critical in order to monitor how best to help the person with dementia. Examples of the content areas covered in a care plan are shown in the box below (for more details see Edberg 2000).

**Rest and activity**

- the patient's sleep pattern
- need for rest periods during the day
- ability to participate in proper activities
- taking past interests as well as present needs into consideration

**Nutrition**

- the patient's ability to eat, taking into consideration the ability to recognize, handle and understand the food on the plate
- the patient's habits: what times he or she wanted to eat, what were his or her dislikes and favorite dishes, did he or she want to eat in privacy or in a group

**Elimination**

- the patient's continence
- use of diapers
- toilet training
- special habits and whether the patient wishes to be alone or not on the toilet
- diseases and medical treatment that could affect the urinary quantity and the patient's ability to stay continent

**Mobility**

- the patient's ability to move in bed
- from bed to sitting
- from sitting to standing and walking
- mobility aids
- mobility training
- occupational therapy
- diseases and medical treatment that could affect mobility

**Clothing, dressing and hygiene**

- the patient's ability to wash him or herself and to get dressed, including gnosis and praxis
- favorite clothes and colors, hairstyle and use of jewelry
- contact and social needs
- abilities to communicate with others (i.e., ability to hear, see, and speak)
- the need for privacy and closeness/distance

**Personality**

- the patient's premorbid personality
- qualities and temperament (e.g., a bad morning mood)

**Special problems**

- Information on any special problems not described in the areas above

From a task perspective, another way to support the professional is to assign responsibility for the long-term care of each person to a primary professional caregiver. Having a single person as the primary caregiver enables that person to build up a strong relationship with the person with dementia and the patient's family.

This promotes:

- the interpretative process
  - being able to understand what the person is trying to say, being able to interpret the meanings behind some of the behaviors (e.g., agitation means needing to go the bathroom)
- a deeper understanding of the patient
  - aberrant behaviors do not necessarily just mean pathology of AD, they reflect something about the patient and are therefore meaningful communications which staff should try to understand
- better cooperation with family members
  - family members learn to trust and work with the professional caregiver and devise ways to improve the quality of life of the person with dementia and strategies to manage BPSD.

Case management is also a useful model for supporting home care. A collaborative relationship developed early in the disease process between the professional, the patient and the family caregiver is vital in the collection of the information required to understand the dementia person properly.

A last method focuses on both the emotional reactions of professionals and the interpretation of the person with dementia from an existential perspective. During supervision and counseling, professionals share their feelings and reactions to specific patients and reflect on what they believe life looks like now for the person with dementia. The participants' reflections can be used to evaluate the current care provisions. Regular group supervision and counseling have been successful in:

- reducing staff burn-out
- increasing job satisfaction
- enhancing staff creativity
- improving the quality of care.

A controlled study combining individualized planned care and clinical group supervision (Edberg 2000; Berg 1994) showed staff improvement in job satisfaction, creativity, and reduced burnout and strain in nursing care. Objective indicators of better care include improved cooperation between the patient and staff, and greater patient activity in spite of disease progression (Edberg 2000).

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- Emotionally supporting staff functions as a regular debriefing as well as a means to create and preserve the image of the patient as a person with a life history and feelings, likes and dislikes.
- 

Palliative care may well be used as a model to care for dementia patients in the late stages. It is prudent to note that patients may sometimes also suffer from other conditions that contribute to suffering and morbidity, for example:

- cancer
- heart disease
- osteoarthritis
- urinary tract infection.

For instance, screaming can be related to pain secondary to osteoarthritis, untreated peptic ulcer, progressive malignancies or even being placed in a chair too long.

## **Conclusion**

Family and professional caregivers are critical to the well being of the person with dementia. Behavioral and psychological symptoms, which are ubiquitous in dementia and are a major source of distress to caregivers as well to the affected persons themselves, can be alleviated. Diagnosis of the cause of behavioral disturbance is always the first step after which there are many strategies to assist caregivers to handle distressing behaviors. These include behavior management, judicious use of medications and changes to the environment. Most importantly, the caregiver is uniquely placed to understand the context in which the behavior is occurring, its meaning, the person behind the behavior and the world of the person with dementia. Caregivers are crucial to the management of BPSD and the management of BPSD is crucial to caregivers.

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# Behavioral and Psychological Symptoms of Dementia (BPSD) Educational Pack



The BPSD Educational Pack was produced by the International Psychogeriatric Association (IPA) under an educational grant provided by Janssen-Cilag. The opinions expressed in the BPSD Educational Pack are those of the contributing authors and are not to be construed as the opinions or recommendations of the publishers or sponsors. Full prescribing information must be obtained for any of the drugs or procedures discussed herein.

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## MODULE 5: Non-pharmacological management

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## **Key messages**

- Non-pharmacological interventions are usually first-line in dealing with milder behavioral and psychological symptoms of dementia (BPSD). There is a limited, but rapidly growing, body of research supporting the use of these interventions.
- Problems without an environmental trigger that are severely distressing to the caregiver require medication often (though not always) in conjunction with non-pharmacological interventions.
- Symptoms that are most responsive to non-pharmacological interventions (Teri et al., 2000; Teri et al., 1997) include:
  - depression/apathy
  - wandering/pacing
  - repetitive questioning/mannerisms.
- The ideal environment for a patient with dementia is one that is non-stressful, constant and familiar.
- A general approach to behavioral interventions includes:
  - identify the target BPSD
  - gather information on the BPSD
  - identify the triggers or consequential events of a specific symptom
  - set realistic goals and making plans
  - encourage caregivers to reward themselves and others for achieving goals
  - continually evaluate and modify plans.
- Recreational, music, and bright-light therapies are interventions that have been shown to reduce anxiety and agitation in other populations. For patients with dementia, reality orientation and music therapies have the strongest research base (Spector et al., 2000a; Woods, 2002), although a number of recent studies have begun to determine the impact of other recreational therapies.
- Psychological and psychosocial interventions including psychotherapy (individual, group and family), when tailored to the individual needs of patients, families, and caregivers, can have a significant impact on patients' well being (Mittleman, 2000; Teri et al., 2000; Teri et al., 1997). Such interventions need to be modified, as individual needs change during the course of the illness.

## **General principles**

Non-pharmacological interventions should be considered as first-line for some of the milder symptoms of BPSD. This module should be studied with Module 4, as caregivers will implement many of the non-pharmacological interventions described here. Thus, to have a significant impact, interventions must be designed so that they can be easily learned and implemented by family or institutional caregivers.

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- Considering cost-containment efforts and the fact that most dementia patients are managed in the home or long-term care settings, low-technology, inexpensive interventions stand the best chance of broad-based implementation and, therefore, widespread impact.
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There are some general principles that underlie non-pharmacological management. First, prior to the initiation of any intervention, it is critical to rule out and treat any potential medical causes of BPSD. Subsequently, it is necessary to continually modify and adapt solutions to the patient's problems, as programs must be tailored to the individual to be most effective.

Caregivers are an essential part of the care of the person with dementia, but often suffer because of the burden imposed by the dementia (see Module 4). As adaptation is central to the success of non-pharmacological interventions, the caregiver has to cope not only with caring for the person with BPSD, but also with the implementation of new strategies. The degree of stress felt by caregivers can impact on their ability to carry out these recommended changes without additional burden. Most importantly, the dignity of patients and caregivers should be respected at all times and their wishes should be considered throughout management programs.

### ***Environmental interventions***

Environmental interventions are based on the recognition that a person with dementia is no longer able to adapt, and thus, the environment must be adapted to the specific needs of the patient. The ideal environment is non-stressful, constant and familiar (Eimer, 1989). If stressful, the environment can contribute to, or exacerbate, BPSD. On the other hand, a supportive environment can alleviate BPSD. (See Appendix C for summary of approaches that have been trialed).

### **Physical environment**

Wandering is a specific BPSD for which a number of recommendations relating to the physical environment have been suggested. Whether it is from home or a nursing home, wandering poses a threat to the safety of the patient and is a source of significant anxiety for caregivers.

Among provisions to decrease dangerous wandering are:

- accessibility to places for ambulation
  - either indoors or in contained outdoor areas
- digital locks to be used by those cognitively intact
- artificial partitions
- electronic bracelets
- electronic alarm systems.

In more general terms, the following environmental variables are helpful in providing a 'non-stressful' environment in patients with dementia:

- use of soft lighting and calm colors such as tan or peach (including the color of uniforms)
- using carpets to absorb sound
- adding appropriate music
- flowing water, pictures, home like settings
- visual barriers (to prevent exiting).

The following are more likely to be deleterious, confusing or frightening:

- abstract/noisy designs which can be confusing or disturbing
- mirrors (outside dressing areas/bathrooms) which may be confusing
- loud telephone bells or paging systems

- frequent re-design or room changes.

## Temporal environment

It is important that the daily schedule of patients suffering with dementia remains as stable as possible since unfamiliar routines can cause stress and consequently exacerbate BPSD (Orrell and Bebbington, 1995). Changes in routine should be as gradual as possible, and caregivers should allow patients time to become familiar with such alterations to daily habits.

Significant sleep-activity disruption occurs even in the early stages of Alzheimer's disease (AD) and increases in severity with increasing disease severity (Bliwise et al., 1993; Vitiello, 1992). Both the physical and temporal environment can affect sleep patterns; however, alterations in circadian rhythm, which can arise from biological or environmental issues (see Module 3), are thought to contribute substantially to the disordered night-time sleep, disrupted sleep architecture and increased daytime napping observed in patients with dementia. The poor sleep pattern results in decreased quality of life for both patients and caregivers and significantly increases the anxiety and exhaustion of the caregiver. This leads to the common caregiver experience of the '36-hour day'.

Sleep is influenced by the amount, and timing, of light exposure. Satlin et al. (1992) administered evening bright-light pulses to patients with AD and disturbance in the sleep-wake cycle. After 1 week, an improvement in the clinical ratings of sleep wakefulness was observed in the majority of patients, with more severe sundowning at baseline predicting a greater clinical improvement.

An increase in daytime physical activity can improve circadian rhythms and be reflected in improved performance and sleep (van Someren et al., 1993). Activity programs including walking programs, may improve disruptive behaviors (Appendices A and C). Passive heating appears to affect sleep in ways similar to exercise. A warm bath in the late afternoon or early evening is known to decrease sleep onset latency and improves sleep quality in young adults. This improvement induced by passive body heating has also been observed in elderly females (Dorsey et al., 1996).

- 
- Establishment of a regular routing, regular physical activity, adequate exposure to light and passive body heating may be useful strategies for improving sleep disturbance.
- 

Management of the temporal environment is particularly important in strengthening the normal circadian propensity for sleep and wakefulness. A component of this is reinforcement of normal time-giving cues (zeitgebers) that help demarcate daytime activities from nighttime activities (Gillin and Byerley, 1990).

### Sleep hygiene programs

Sleep hygiene programs are generally based on strategies geared to strengthen circadian rhythm status by maximizing cues to the brain's time-keeping system in addition to creating the most favorable physical environment for sleep.

- 
- The National Institutes of Health (NIH) Development Conference Consensus Statement (NIH, 1990) notes that sleep hygiene is a common medical and lay treatment practice, the value of which should not be underestimated for the treatment and prevention of sleep disturbances.
- 

Recommendations of the Consensus Statement (NIH, 1990) include:

- maintaining regular bedtimes and rise times
- using the bedroom primarily for sleeping
- regular timing of meals
- avoiding alcohol, caffeine and nicotine
- reducing evening fluid intake
- engaging in a bedtime ritual
- minimizing light and noise at bedtime and throughout the night.

Certain medications (such as diuretics and some antidepressants) taken at night should also be avoided.

Reducing the time insomniac persons without dementia spend in bed improves numerous indicators of sleep quality (Freidman et al., 1991). The cornerstone of sleep restriction therapy is the belief that excessive time in bed perpetuates insomnia. Although it has been hypothesized that sleeping quality might be improved in patients with dementia by sleep restriction therapy, this is yet to be proven. In AD patients, it may be beneficial to take a consolidated afternoon nap (i.e., to work with the biphasic circadian sleepiness rhythm) rather than to attempt to override the endogenous sleep tendency (i.e., to work against the rhythm).

## **Sensory considerations**

Normal changes that occur with aging affect both visual and auditory perception. Sensory deficits are normal in healthy elderly individuals, but in people with dementia they are less likely to be evaluated and appropriately treated. It is important to keep in mind that in persons with dementia sensory deficits will be exacerbated compared with non-demented elderly individuals, because of difficulties with orientation due to cognitive impairment.

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- Patients with dementia may become fearful, anxious or restless because they cannot properly see or hear their environment. Thus, patients need to be examined routinely to evaluate vision and hearing.
- 

The pupils of elderly persons have decreased ability to accommodate and thus cannot adjust readily to dark environments. Also, the yellowing of the lens results in diminished ability to perceive different colors, an effect that has fewer consequences in environments incorporating brighter hues. In addition, cataracts and glaucoma, which develop commonly, can contribute to disorientation. Contrasts need to be more vivid to be discerned, especially where there is a possibility of falling e.g. stairs.

Hearing decrement often occurs and, if uncorrected, is associated with increased rates of paranoia in the elderly. Appropriate intervention, such as provision of a hearing aid, should be made if a hearing deficit is diagnosed; although patients with more advanced cognitive deficits may need assistance to ensure correct usage. It is important to remember that a demented person with a hearing impairment is less likely to communicate even if a hearing aid is prescribed, and also more likely to misplace or lose the aid or to use it inappropriately.

## **Nutritional considerations**

It has been reported that up to 92% of patients with dementia will experience significant weight loss compared with age-matched, non-demented controls. Patients with dementia may forget to

consume food in a timely manner and may not pay attention to hygienic storage of their food. Taking time to assist cognitively impaired patients with eating and reminding them to eat are therefore important.

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- The types of food that may be consumed (e.g., low fat, low salt diets) and consistency of food (e.g., mechanical soft diet) may contribute to under nutrition because these can be rather unappetizing, especially in institutional settings.
- 

Eating has significant social meaning. Patients with mild to moderate dementia may be reluctant to be part of social situations because of awareness of their deficits, especially if they also have a hearing or visual impairment. These patients should be given support and encouragement to join in, and, if possible, arrangements changed to better suit their needs.

Specific BPSD are associated with the risk of under nutrition in different ways (see box below).

When patients have altered perceptions they may stop eating because of paranoid and delusional ideation about food and fluids. Treatment of the underlying psychotic process will help.

Very apathetic, cognitively impaired patients may be at severe risk for weight loss, as they lack initiative to eat. Recognizing patients at risk, and taking time to help them at meal times, are essential.

Weight loss can occur in patients with aggressive behavior if they are intent on throwing all meals and fluids on the floor or at caregivers, and caregivers are reluctant to approach them to assist with feeding. Teaching caregivers ways to pacify these patients during meal times and not sticking rigidly to set meal times, thereby giving the patients more freedom of choice, can be helpful.

Persons with dementia who show BPSD of pacing and wandering often experience weight loss, although the loss cannot be attributed to increased activity per se. Such patients appear to consume as much food as their less restless counterparts. Help with weight maintenance can be achieved by:

- making food available for brief snacks
- using behavioral interventions aimed at decreasing agitation.
- paying attention to personal tastes i.e. ensuring that favorite foods are provided while foods that the individual always disliked are avoided

## ***Behavioral interventions***

When seeking to deal with BPSD using a behavior-modifying intervention, the following general approach may be beneficial (Teri and Logsdon, 1990):

- Identify the target BPSD
  - a clear definition of the problem to be addressed is the first step in modifying behavior. The more clearly caregivers can define the problem, the more likely it is that they will be able to identify an effective course of action
  - close collaboration with the caregiver is usually necessary to identify a specific problem
  - it is better to tackle one BPSD at a time.

- Gather information about the BPSD (see also Module 2)
  - how often does the BPSD occur?
  - when does it happen?
  - where does it happen most?
  - in whose presence does it occur?
  - ask the caregiver to record the answers to these questions over 1–2 weeks
  - daily diaries are useful to understand the occurrence, frequency and severity of a target BPSD and to help formulate treatment plans.
  
- Identify what happens before and after a target BPSD
  - although the caregiver's impression may be that the problem BPSD happens 'out of the blue', careful observation of events immediately preceding the behavior can identify trigger factors
  - BPSD are rarely simple – usually several factors are involved in triggering a behavior and the more caregivers understand the inter-relationship of these factors, the more likely they are to intervene successfully.
  
- Set realistic goals and make plans
  - involve the patient as much as possible and work with the caregiver to set treatment goals
  - start with a small achievable goal and proceed step by step
  - tailor the plan to the individual patient and caregiver
  - be practical and allow plenty of time for change to occur – do not expect major changes overnight
  - work with the caregiver to anticipate problems that might occur and how they might be solved
  - if possible, have the caregiver generate several alternative plans and then decide which one to try first.
  
- Encourage caregivers to reward themselves and others for achieving goals
  - it is very important for caregivers to reward themselves for achievements, no matter how small
  - the patient will also benefit from rewards for their achievements.
  
- Continually evaluate and modify plans
  - treatment plans need to be continually monitored to determine how successful they are
  - decide how you will ascertain whether the plan is working (e.g., by monitoring the number of times the BPSD occurs, or the length of time for which it occurs)
  - caregivers need to be consistent and flexible in carrying out plans – i.e. they need to persevere with a chosen approach initially, but should not persist to the point of confrontation if the approach is clearly not working
  - if strategy 'A' has not worked, the caregiver and the clinician need to implement strategy 'B' and so on.

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■ **The 36-Hour Day** written by Mace and Rabins (1991) is an excellent guide for caregivers. It provides practical guides and suggestions for caring for patients with dementia and coping with BPSD.

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### **For depression**

While behavioral interventions can alleviate mild depression, patients suffering from moderate and severe depression often require an antidepressant (see Module 6). Behavioral interventions and pharmacotherapy are therefore often used in combination (Teri, et al., 2000; Teri, et al., 1997).

### **Recommended strategies**

- Increase and encourage activities that the dementia patient can enjoy. A good way to begin is by identifying activities that the person enjoyed in the past and modifying them appropriately to the person's current level of functioning. Teri and Wagner (1992) have shown that pleasurable activities decrease depression in demented patients, utilizing a wide range of adjunctive experiences in the context of individual psychotherapy.
- Confirm that the activities the caregiver believes are enjoyable really are those that the patient enjoys. Consult the patient and observe his/her behavior.
- Plan pleasant activities to be conducted with someone whose company the patient enjoys, particularly if the person complains of feeling isolated or lonely:
  - Encourage the patient to talk about pleasant things, both past and present: turning someone's thoughts to happy events and helping them remember good things can cheer them (it can also make them feel more depressed thinking of what has gone before, and so a degree of sensitivity is required).
- Provide a bright and cheerful environment.
- Individualize all of the above approaches to the person's needs and situation.
- Take care to maintain the caregiver's mental and physical health – it is difficult and sometimes depressing to be constantly with someone who is depressed.

### **For agitation and aggression**

Behavioral interventions for agitation and aggression can be very helpful and in milder cases can defuse or prevent the aggressive behavior. In severe cases, however, a short-term pharmacological intervention (see Module 6) may be needed alone or in combination with the non-pharmacological intervention (Teri, et al., 2000). Many strategies have been tried (see references in Appendix B); results vary and different methods may suit different patients:

- ◆ music, especially if individualized to the person's previous tastes
- ◆ audio-tapes of family members talking to the person with dementia
- ◆ use of video-tapes
- ◆ hand massage
- ◆ therapeutic touch
- ◆ aromatherapy – e.g. lavender oil
- ◆ sensory integration
- ◆ enhanced social interaction

### **Recommended strategies**

- Intervene early – by recognizing a problem situation and intervening before it becomes a crisis, caregivers can avoid many instances of agitation and aggression.
- Try to keep the patient away from situations and individuals that are provoking.
- Encourage caregivers to use a reassuring and gentle voice – it can help to defuse a situation by calming the person.
- An agitated person should be approached slowly and calmly from the front. Caregivers should tell the person what they are going to do and try not to startle them.
- Use touch judiciously – sometimes a touch or a hug can be comforting to an agitated person, but for another it could be provoking.

- Use non-threatening postures when dealing with an agitated patient. Standing over a patient who is seated or in bed can be frightening and may provoke anger. Caregivers should bend from the knees, kneel or sit down so that they are at the patient's eye level.
- Distract the person with questions about the problem and gradually turn their attention to something unrelated and pleasant – change activities, go to another room and leave the situation for a while.
- Establish a calm, quiet environment (see pages 8–10).
- Avoid arguing and trying to reason while the patient is agitated – arguing almost always causes the agitation/aggression to escalate. Back off and avoid confrontation whenever possible.
- Avoid physical restraint wherever possible. Restraints can increase the patient's perception of threat and escalate agitation.
- Caregivers should always get help immediately if they are in danger. They should be given emergency numbers to call and be strongly encouraged to use them if they feel threatened.

### **For wandering**

There are many reasons for wandering(see also Module 2): aimless, purposeful (e.g. in order to abscond from residential care), as part of a general agitation, as a symptom of depression or even as reaction to medication, i.e. akathisia. Where no specific cause can be discovered and treated, behavioral interventions can play an important role in the management of wandering.

### **Recommended strategies**

- Confused persons will often forget that they are supposed to be at a particular place and so require frequent reassurance about where they are and why they are there.
- If a patient who is going to be moved is able to understand what is going on, involve him or her in planning the move and visit the new setting beforehand. In more severely confused patients, it may be easier not to introduce them gradually, but to make the move as quickly as possible and without any fuss.
- Day care centers and nursing homes have found that people adjust best, and are therefore less likely to wander, when:
  - they do not stay long for the first few visits
  - the caregiver stays with them the first few times
  - someone from the program visits them at home before the transition.
- If the person is getting lost, and can still read, understand and follow instructions, give him or her a pocket card. The instructions on the card should be simple and might include a reminder, 'Stay calm and don't walk away, or 'Call home'--and a telephone number. Different cards may be needed for different trips.
- Patients who wander should wear a bracelet with the statement 'Memory impaired'. A bracelet that is securely fastened, so the patient cannot remove it or slip it off, may be better than a necklace.

### **For repetitive questioning/mannerisms**

Repetition of questions or actions by confused people can be extremely irritating or distressing for caregivers; however, it is unlikely that either reasoning with the patient (which is generally futile) or confronting the patient (which can exacerbate the behavior) will be beneficial.

### **Recommended strategies**

- Consistently ignoring repeated questions can work with some patients, but it will upset others who may become angry because they were not answered.

- Sometimes the person may be unable to express what is actually worrying him or her. For example, if a patient continues to ask for someone who is dead, he or she may be trying to express a feeling of being lost:
  - caregivers can react to this emotional aspect, explaining that they will take care of the patient
  - they could also distract the patient, either by asking him or her about something related or unrelated.
- If a patient is continually repeating a task, he or she can be distracted by being given a new and specific task to perform. It is important that the caregiver does not appear to pressure the patient or sound upset; in such situations, a catastrophic reaction can be precipitated.
- Providing positive attention for more appropriate behaviors will encourage these behaviors.
- Occasionally, the patient responds only to agreement by caregivers or being distracted by a lie, for example, telling the patient a deceased friend or relative will be coming later.

### **Case study**

Mary, who has been in an Alzheimer unit for a 3-week period of respite care, is due to go home today. She repeatedly insists to the staff that she must go and collect her daughter from boarding school for the holidays. Mary knows that she is to see her daughter again today and that there is to be some sort of change in living arrangements.

Settling into the respite unit and now preparing to go home again may have exacerbated Mary's temporal disorientation. In these circumstances her agitation may be worsened if she is confronted or corrected. Instead, it is appropriate to reassure her that her daughter is coming directly to the unit and that they will be going home together. Once they get home and Mary settles back into her familiar surroundings, her orientation may well improve (Swanwick, 1995).

### **For inappropriate sexual behavior**

Inappropriate sexual behaviors in people with dementia are uncommon. More common is the incorrect belief that these occur in 'senile' people. It is important to consider that, however infrequent the occurrence, accidental self-exposure and aimless masturbation are behaviors that caregivers find distressing and embarrassing. Behaviors may occur because the patient has forgotten where he is, how to dress or the importance of being dressed. However, it is also important to consider that undressing may also occur if garments are uncomfortable, and handling of the genital area may occur if the patient has a urinary tract infection, itching or discomfort.

### **Recommended strategies**

- If a patient is undressed:
  - calmly bring the patient a robe and, matter-of-factly, help him or her to put it on.
- If a patient is found masturbating:
  - try not to act upset or distressed and avoid confrontations, as this may precipitate a catastrophic reaction
  - gently lead the person to a private place
  - distract the patient by providing something else to do
  - prevent future episodes by increasing involvement in on-going activities.

## ***Recreational, adjunctive and social therapies (See Appendix B)***

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- Unlike many medically ill patients in nursing homes who are frequently debilitated and inactive, patients with dementia are physically able to walk about and seek stimulation.
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In the past, the need for social and recreational therapies has been overlooked; however, such activities are now widely incorporated into the daily management of patients with dementia and BPSD. An activities program can provide structure to the patient's day, preserve remaining capabilities, minimize the consequences of cognitive and functional deficits, and create an environment for social interaction.

The efficacy of such a program was evaluated in a study by Rovner et al. (1996). Each day, from about 10 a.m. to 3 p.m., patients in the intervention group were taken to an activities room in the nursing home where they engaged in various physical and social activities. The study supported the use of such interventions to reduce the prevalence of BPSD and the need for restraints or psychotropic medication.

Gerdner [2000] reviewed the literature of similar interventions. This review indicates that, for patients with dementia, music has the strongest research base, although a number of recent studies have begun to determine the impact of other recreational therapies. Music, reality orientation, reminiscence, and validation therapies have all been the subject of Cochrane database systematic reviews. The strongest evidence was found for reality orientation [Spector et al., 2000a]. Reviews of music [Koger and Brotons, 2000], reminiscence [Spector et al., 2000b], and validation [Neal and Briggs, 2000] therapies were not able to identify reliable statistical evidence of significant impact but were suggestive of beneficial effects in treating or managing dementia symptoms. The predominant conclusion of these reviews is the need for additional well-designed studies of such interventions.

### **Music therapy**

Research shows that **background music** reduces anxiety for a wide range of medical illnesses (including post surgical coronary care patients, obstetric or arthroscopic surgery patients and dental patients [post surgery]) and reduces nausea and vomiting in cancer chemotherapy patients. Background music also has been shown to decrease persistent auditory hallucinations in patients with chronic schizophrenia.

Because the neostriatum, which is involved in musical memory and coordination, is one of the last parts of the brain to deteriorate in AD, even patients with severe AD may retain musical abilities and the capacity to participate in musical activity. Thus, it is reasonable to expect that background music will allay anxiety and decrease agitation for patients with BPSD, although research has yet to determine how often music needs to be played and for how long a period. Preliminary evidence suggests that the most effective music is non-heavily percussive, from the patient's teen years, and from his or her own country. Music tailored to the patient's individual tastes is more effective in reducing agitation (Gerdner et al, 1999)

**Music therapy** can lead to:

- reduction in anxiety and restlessness
- sleep induction
- reduction in hostility.

Specific techniques include:

- providing simple musical accompaniments
- moving or dancing to music

- stress reduction through music (Hanser, 1996.).

### **Other therapies**

Anecdotal reports have suggested that a number of other activities and therapies are helpful for some patients, although, to date, no studies have been performed to evaluate this systematically.

Examples of these adjunctive approaches are:

- religious activities
- pet therapy
- art therapy
- movement therapy.

## ***Psychological interventions***

### **Individual psychotherapies**

Many patients need help structuring their lives, giving up previous activities, and becoming involved with activities that they still have the capacity to perform. They may also need assistance acknowledging their fearfulness of being exposed to social situations and in overcoming these anxieties or adjusting to a reduction in their social life.

Patients with early and mild AD can benefit from individual psychotherapy. Many are frightened about their cognitive losses and have insight to realize the nature of their problems. Later on in the illness, denial is more prominent, and insight is commonly lost. Patients can benefit from an empathic and information-driven approach that helps them to focus on their feelings, the practical aspects of their illness and their mourning response to their cognitive deficits.

The most important factor in successful psychotherapy is the capacity to form an affective attachment. Many patients develop an idealized transference with the therapist and feel protected and less anxious knowing that the therapist is available (Finkel, 1979).

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- Caregivers will report that even though a patient may not remember the details of the session, the empathic relationship and sense of reassurance can result in the patient being calmer for hours or even days following the session.
- 

When patients embark on an individual course of psychotherapy, a comprehensive evaluation must take place. A complete history should be taken and incorporated with information provided by caregivers. This information is especially important in adapting psychotherapeutic interventions.

### **Family psychotherapy**

The decline of a parent's cognitive function represents a crisis for the entire family. Even for the closest of families, it may create tensions and conflicts, although these are customarily resolved. For those families where certain members are alienated, the crisis can result in renewed contact, which, in turn, leads to opportunities to resolve old family conflicts, or results in additional

fragmentation and hostility, often with disastrous consequences. Often old sibling conflicts are revived.

Family members will respond to this loss of a parent (which is accompanied by the sense of loss of a powerful individual who is protective and nurturing) in vastly different ways. For some it causes great panic, others use denial, some accept this in a matter-of-fact way, while some families are drawn more closely together as they struggle to deal with the BPSD. The family requires information about the illness, as well as techniques for dealing with a range of management problems.

It is best to meet with all family members together. If certain siblings are not present, they may be the ones that have difficulty with the consensus recommendations. Typically, it is best to see the family at the last session of the day, for two reasons:

- there may be few opportunities to get everybody together
- once members become involved, discussions may last for a considerable period of time before resolution.

Caregivers, especially the primary caregiver, need a great deal of encouragement to maintain a life outside caring for the person with dementia (see also Module 4). Caregivers are at particular risk of developing major depression and a number of stress-related illnesses (e.g., hypertension, ulcers). Often caregivers will feel guilty about taking care of themselves, and it is important to assure them that when they take care of themselves, they are actually taking care of the ill family member. If they are strong and healthy, they are in the best position to maintain their current life situation. It is not uncommon for caregivers to also feel guilty when they require additional services. This can begin with sitters, leading to adult daycare services, and eventually nursing home placements. Caregivers also need help in dealing with their anger, both at their demented family member, as well as with their life circumstances (see box).

- Psychosocial interventions should be tailored to the individual needs of patients, families and caregivers. Such interventions need to be modified as individual needs change during the course of the illness and involve helping them to accept the diagnosis and deal with realistic limitations
- ensuring issues revolving around finances, which can lead to agitation, are understood and dealt with realistically
- adapting effective coping strategies (e.g., knowing when to insist on a patient's cooperation and when to back off)
- accepting role changes, especially increasing dependence
- altering environments so they are less likely to be traumatic to the patient and thus less likely to result in BPSD
- obtaining more informal and formal support (possibly including support groups from a local AD association)
- dealing effectively with issues surrounding other caregivers who may have their own ideas about treatment strategies.
- As the illness progresses, the caregiver will need help in the grieving process and with ethical issues involving conflict between safety and allowing autonomy.

### **Group psychotherapy**

Early studies of group therapy conducted in patients who were demented demonstrate that patients with very early or mild AD can benefit from group contact with others who face similar circumstances and have similar emotional challenges dealing with their cognitive loss (Yale, 1995).

Mixing together patients with depression and dementia does not work well because depressed patients feel threatened and those with cognitive deficits feel intimidated by their comparative lack of cognitive abilities. This aside, discussing one's feelings, clarifying issues, finding ways to direct activities, and dealing with loss under the supervision of an experienced therapist are important components of treatment and facilitate adjustment and improved quality-of-life. Information to date on group therapy for demented individuals is, however, based on clinical description and anecdotal information, rather than on proved research.

### **Team approach**

Several studies, principally in residential care settings, have demonstrated that a team approach and provision of consultancy can significantly decrease challenging behaviors. This may involve case management, implementation of individual treatment programs, nurse education or behavioral management strategies or a combination of these.

### ***Conclusion***

Behavioral and psychological symptoms are ubiquitous in dementia. Many non-pharmacological strategies are effective in reducing, eliminating or even preventing these behaviors. The focus may be on the environment, the staff, the family or the patient. More often it is a combination of different approaches. The challenge is not the behavior but its management. Meeting the challenge requires creativity, ingenuity often and empathy - a humane understanding of the world of the person with dementia. Frequently several approaches are required before the successful one is discovered. A team approach involving professionals, all residential staff (including non-clinical and domestic staff) and families is best. Physicians have an important role in excluding other causes of BPSD (see module 2) and in being part of the management team.

## **Appendix A: Sample nursing care plans for patients with BPSD**

This appendix includes some useful examples of ways in which care plans incorporate different non-pharmacological interventions in the management of patients with BPSD.

### **Nursing diagnosis: Sensory perceptual alteration (visual, auditory, tactile)**

Signs and symptoms: Hallucinations, delusions, and disorientation.

<b>Intervention</b>	<b>Rationale</b>
Express concern and care for the agitated patient. Remain close by until the patient becomes calm.	These measures provide support and help relieve the patient's fears.
Allow the patient to express thoughts, continue talking with them and express concern while maintaining eye contact.	Comforting a patient often helps alleviate the delusions or hallucinations.
Keep a night light in the patient's room.	Agitation and hallucinations may worsen at night because of perceptual disturbances. Use of a night light can be soothing.
Remove extraneous stimuli, such as televisions and radios, from the environment if necessary.	Extraneous stimuli may initiate visual, auditory or tactile hallucinations or impair the patient's ability to receive important stimuli.

#### Outcome criteria:

- the patient will not become agitated
- the patient will function safely within the environment.

**Nursing diagnosis: potential for violence directed at others**

Signs and symptoms: Demanding attention, committing overtly aggressive acts, accusing others falsely.

<b>Intervention</b>	<b>Rationale</b>
Exclude pain or physical discomfort as a cause of violent behavior during assistance with dressing, toileting etc,	In severe dementia, hitting out may be the only means of communication when the patient has pain [e.g. on moving an arthritic joint during dressing]
Listen actively to the patient, remain honest, calm, clear and concise during interactions. Ensure appropriate eye contact and facial expressions.	This establishes a sense of trust, conveys attention and concern and facilitates communication.
Do not rush the patient or overly structure the environment.	Tension commonly results from feelings of being forced or pushed to act in a certain way.
Remove all potentially harmful items from the patient's reach.	The patient may use objects within the environment to injure others.
Reinforce non-violent behavior	Rewarding positive behaviors discourages negative outbursts.
Encourage the patient to do as much as possible for him or herself.	Invading the patient's personal space may cause physical aggression.
Promote regular exercise.	Regular exercise helps control and channel the patient's energies.
Avoid arguing or trying to reason with the patient.	The patient cannot appreciate another point of view at such times.
Do not use aggression or make threats when dealing with patients.	A calm approach is important in reducing the potential for aggression.

**Outcome criteria:**

- the patient will begin to control the behavior with the assistance of others
- the patient will have fewer violent responses.

**Nursing diagnosis: altered patterns of sexual behavior related to cognitive impairment**

Signs and symptoms: Inappropriate sexual activity, confusion about inappropriate behavior, sexual exposure.

<b>Intervention</b>	<b>Rationale</b>
If the patient makes inappropriate advances, casually refuse their overtures, then try to distract them. Avoid negative overreactions.	The patient with cognitive impairment typically loses the capacity to understand social rules. Avoiding overreactions helps prevent violent or verbal abusive episodes.
If the patient undresses in public, change clothing type or fasteners (e.g. buttons at the back of a garment, rather than the front).	Altering clothing style decreases the risk of inappropriate exposure.
If the patient masturbates in public, distract and remove him or her from the area.	Such behavior often embarrasses people or staff observing it.
Encourage the patient to participate in physical activities.	This will direct sexual energy toward productive physical activity, thereby reducing the potential for inappropriate sexual behavior.

Outcome criteria:

- staff will implement measures to prevent or reduce the incidences of inappropriate sexual behavior
- staff will cope effectively with the patient's sexual behavior
- the patient will have an outlet for sexual feelings and needs.

## **Appendix B: Recreational adjunctive and social therapies**

(Burns, 2002, Gerdner, 2000; Opie et al, 1999) with additional references\*

### **PHYSICAL ENVIRONMENT**

<b>Authors</b>	<b>Target BPSD</b>	<b>Intervention</b>	<b>Main results</b>
Chafetz et al 1990	Exiting behavior	Strips of contrasting colored tape laid on floor before doors	Exiting behavior not decreased
Cohen-Mansfield & Werner, 1998	Agitation, pacing, trespassing and exiting	“Nature scene” and “Home and people” environments created in nursing home corridors	Significant increase in time spent in enhanced environments, non-significant reductions in trespassing, exiting and agitation
Dickinson et al, 1995	Exiting behavior	Door obscured by same color blind or cotton sheet	Exiting behavior decreased
Mayer & Darby, 1991	Physical contact with door	Full-length mirror in front of door	Decrease in physical contact with door
Namazi et al, 1989	Exiting behavior	7 types of visual barrier – colored strips of tape, hiding doorknobs using cloth, paint or secure cover	Tape increased exiting, other interventions decreased exiting
Negley & Manley, 1990	Aggression during elevator transfer to meal room	Meals provided in day rooms (making transfer unnecessary)	Assaults reduced
Whall et al, 1997	Agitation and aggression during bathing	Bathrooms enhanced with tape recordings of birdsong, flowing water and small animals and large bright pictures, residents offered pudding and soft drinks, nursing aides trained	Significant decline in agitation and aggression

### **ACTIVITY PROGRAMS**

<b>Authors</b>	<b>Target BPSD</b>	<b>Intervention</b>	<b>Main results</b>
Cohen-Mansfield & Werner, 1997	Verbal disruption	Audiotapes of preferred music Video tapes of family members talking to the older person Social interaction	Significant decreases in verbally disruptive behaviors compared to control non-intervention
Holmberg, 1997	Wandering	90 minute walking program weeknights	Significant drop in aggressive incidents
Namazi et al, 1994	Agitation	Daily 40-minute physical activity program	Agitation episodes decreased significantly compared to controls
Robichand et al, 1994	Agitation	Sensory integration training for residents	Non-significant improvements in both groups
Zisselman et al., 1996	Behavioral disturbances	Persons assigned to a pet therapy intervention group or an exercise control group for 1 hour per day, 5 consecutive days	No significant differences between or within groups before and after the intervention

## MUSIC, VOICE AND LANGUAGE

Authors	Target BPSD	Intervention	Main results
Burgio et al., 1996	Verbal agitation	Audiotapes of babbling brooks or ocean waves, preferred music	Decreased verbal agitation
Camberg et al., 1999*	Agitated or withdrawn behaviors	Audiotape by family members or staff of memories in the format of a telephone conversation compared to audiotapes of emotionally neutral newspaper articles and usual care	Significant reduction in staff reports of agitation and withdrawn behaviors compared to controls, but not on direct observations
Clark et al., 1998	Aggression	Audiotapes of preferred music played during bath times	Significant reduction in aggressive behaviors
Denny, 1997	Agitation	Classical music played for 1 ½ hours in the dining room during the noon meal during alternating weeks	Statistically significant reduction in agitated behaviors during the presentation of music
Devereaux, 1997	Agitation	Individualized or preferred music played for 30 minutes on 5 consecutive days for 1 week	Reduction in agitation during the intervention and the 30 minutes immediately after the intervention
Gerdner et al., 1999	Agitation	30 minute audiotapes of individualized music or classical relaxation music twice a week for 6 weeks	Significant reduction in agitation during and following individualized music compared to classical
Hall & Hare, 1997	Agitation	A commercially prepared video that incorporates “familiar music” and “common memories” was presented.	No significant difference in agitated behavior. A slight increase in positive behavior reported during the observation period.
Ragneskog, et al., 1996	Agitation/ Depression	Music played from five minutes before dinner until last person left dining room	Increased food intake during music, particularly for desert; reduction in irritability, fear-panic, and depressed mood
Remington, 1999	Agitation	Persons assigned randomly to one group: 1) calming music; 2) hand massage; 3) calming music and hand massage; 4) control.	Each experimental intervention produced a significant reduction in agitation compared with the control group. The benefit was sustained and increased over time.
Tabloski, et al., 1995	Agitation	Two 15-minute presentations of music (Pachelbel's Canon in D) approximately one week apart	Reduction in agitation during and after the music intervention
Thomas et al., 1997	Aggression	Selected music based on the patient's personal preference as reported by a family member	Significant reduction in aggressive behavior but, hiding/hoarding, physically non-aggressive and, verbally agitated behavior not reduced.
Woods & Ashley, 1995	Problem behaviors	Audiotapes by family members recounting cherished memories played twice a day	Problem behaviors reduced significantly while tapes were played

## BEHAVIOR THERAPY

Authors	Target BPSD	Intervention	Main results
Bird et al, 1995	Individual problematic behaviors	Cued recall – signs and staff involvement	Reduction in problematic behaviors
Doyle et al, 1997	Disruptive vocalization	Contingent reinforcement rewarding quiet behavior, ignoring outbursts and distraction with music, conversation, touch or visual aids	Significant reduction in noisiness
Gormley et al, 2001*	Aggression	Four session behavioral management training for caregivers in their own homes compared to 4 sessions of discussion on care-related issues	Non significant trend towards reduction in aggressive behavior in behavioral management group
Moniz-Cook et al, 2001*	Aggression and agitation	Systematic analysis and targeted intervention involving nursing home staff	Reduction in aggression and agitation
Teri et al, 2000*	Agitation	8 weekly and 3 biweekly structured behavioral management training sessions for caregivers compared to haloperidol, trazodone and placebo	No significant differences between haloperidol, trazodone, behavioral management and placebo. Modest reductions in agitation in all groups

## MASSAGE AND AROMA

Authors	Target BPSD	Intervention	Main results
Ballard et al, 2001	Agitation	Melissa oil (10% by weight combined with base lotion) via cream applied to hands twice daily	Significant improvement as measured by Cohen Mansfield agitation inventory
Brooker et al, 1997	Agitation	Series of 30-minute hand massage or lavender aromatherapy	¼improved, 2/4 worsened
Holmes, et al, 2002	Agitation	2% lavender oil via aromatherapy stream daily	Significant improvement as measured by Philadelphia agitation scale, with 60% of patients having some benefit
Smallwood et al, 2001*	Behavior disturbance	Aromatherapy + massage, plain oil massage and conversation + aroma compared	Aromatherapy + massage showed greatest reduction in agitation significant between 3-4pm compared to conversation + aromatherapy
Snyder et al, 1995	Agitation	10-minute hand massage and therapeutic touch	No reduction in agitated behaviors
Snyder et al, 1995	Agitation	Hand massage twice a day	Significant reduction in agitation, though not all behaviors reduced, effect only in females

## LIGHT THERAPY

Authors	Target BPSD	Intervention	Main results
Colenda et al, 1997	Sundowning	2 hour morning exposures to 2000lx light worn on the head 3-4 cm from the eye	No reduction in agitation
Graf et al, 2001	Sundowning	Randomized evening bright light or dim light therapy	Increase in mini-mental state exam scores and phase shift in body temperature rhythm
Haffmans et al, 2001*	Agitation	2X5 consecutive morning exposures to 30-minutes 10,000lx bright light and randomly administered 2.5gm melatonin or placebo at 22.00h	Bright light 30 +/- placebo showed significant decrease in agitation, but no reduction in melatonin group
Lovell et al, 1995	Sundowning	2hour morning exposures to 2500 white fluorescent light	Significant reduction in evening agitation
Lyketsos et al, 1999*	Agitation	1 hour morning exposure to 10,000 lx bright light for 4 weeks	Length of sleep of residents improved significantly. No change in other behaviors
Satlin et al, 1992	Sundowning	3 hours evening exposures to 1500-200lx fluorescent light for a week	Reduction in restlessness that increased again after treatment was stopped

## MULTI-DISCIPLINARY TEAMS

Authors	Target BPSD	Intervention	Main results
Brodady et al, in press*	Depression and Psychosis	Psychogeriatric case management included psychotropic management, supportive therapy, pleasurable activities and behavior management compared to consultation or standard care	No significant differences between groups. Subjects in all groups improved.
Hinchliffe et al, 1995	Behavioral disturbance	Team implementation of individually tailored treatments including psychotropic medications, activities, behavioral strategies and carer education	Significant improvement in 15/20 of intervention group, but only 2/13 of wait-list group improved after intervention
Hughs & Medina-Walpole, 2000*	Behavioral disturbance	Team management including systematic behavioral observation, pharmacological and non-pharmacological interventions.	Reduction in behavioral disturbance (partly attributed to better medication use)
Opie et al, 2002*	Challenging behaviors	4-week team management including psychosocial strategies, nursing approaches, psychotropic medication and pain management	Consultancies significantly significant decrease in challenging behavior compared to controls. Both groups improved.
Proctor et al, 1999*	Behavioral disturbance	Seminars for care staff by outreach team, weekly visits from psychiatric nurse.	Significant improvement in depression, but not on behavioral rating

Rovner et al, 1996*	Behavioral disturbance	Program included activities, guidelines for psychotropic medications and educational rounds	Significant reduction in prevalence of behavioral disorder compared to controls
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## CARER EDUCATION

Authors	Target BPSD	Intervention	Main results
Bourgeois et al, 1997	Repetitive verbalizations	Training family carers to use individualized written cues to prompt memory. Included 3-hour behavioral management principle workshop and 11 1-hr weekly home visits.	Significant decrease in repetitive verbalizations
Burgener et al, 1998	Behavioral disturbance	Carer education on behavior	Statistically insignificant reduction in behavior
Hagen & Sayers, 1995	Aggression	Three 30-minute in-services for hospital staff (including housekeeping and recreational staff)	Significant reduction in incidents of resident aggression
Haupt et al, 2000*	Agitation and anxiety	12 weekly 90-minute group psycho-education for caregivers	Significant improvement in agitation and anxiety
Matthews et al, 1996	Behavioral disturbance	Workshops on client-oriented approaches, residents given freedom to rise from bed, take their meals and participate in activities	No changes in aggression and non-physical agitation, daytime sleep increased, verbal disruption in the mornings decreased

## PSYCHOLOGICAL THERAPIES

Authors	Target BPSD	Intervention	Main results
Baines et al, 1987*	Problem behaviors	Reminiscence groups	Reduction in problem behaviors
Fine & Rouse-Bane, 1995	Difficult behaviors	Care staff trained in validation therapy – listening, distraction, eye contact, emotional expression and other techniques	Reduction of reported incidents attributable to difficult behaviors of 3%
Gibson 1994*	Behavioral disturbance & agitation	Reminiscence groups – both dementia specific and mixed (for any residential care resident)	Behavioral disturbance rare in mixed groups. Staff report less agitation for some individuals outside group.
Gibson 1994*	Troubled or troubling	Individualized care plan including reminiscence therapy	Decreased aggression and demanding behaviors
Goldwasser et al, 1987*	Behavior and depression	Twice-weekly reminiscence and support groups for 5 weeks	No differences on behavior between intervention and no-treatment controls. Significant reduction in depression post-intervention, but lost at 6-week follow-up

Welden & Yesavage, 1982*	Behavioral problems	Relaxation instructions including progressive muscle relaxation and self-hypnosis techniques	Significant improvement compared to discussion group controls. 40% no longer required sleeping tablets
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# Behavioral and Psychological Symptoms of Dementia (BPSD) Educational Pack



The BPSD Educational Pack was produced by the International Psychogeriatric Association (IPA) under an educational grant provided by Janssen-Cilag. The opinions expressed in the BPSD Educational Pack are those of the contributing authors and are not to be construed as the opinions or recommendations of the publishers or sponsors. Full prescribing information must be obtained for any of the drugs or procedures discussed herein.

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## MODULE 6: Pharmacological management

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## **Key messages**

- In general, non-pharmacological approaches are first-line treatment for behavioral and psychological symptoms of dementia (BPSD).
- For BPSD that are moderate to severe and which impact on the patient's or the caregiver's quality of life or functioning, medication is clearly indicated, often in conjunction with non-pharmacological interventions.
- In elderly patients with dementia, dosages of medication will generally be lower than those used in younger patients and in older non-demented people, although the elderly are a heterogeneous group requiring an individualized approach to dosing.
- Antipsychotic medication is most effective in the treatment of psychotic symptoms (hallucinations, delusions) and behavioral symptoms, such as physical aggression.
- Newer antipsychotic medications appear to be at least as effective as conventional neuroleptics, but have fewer side effects.
- Antidepressant medications are underused in people with dementia, despite the common occurrence of depression in dementia and the documented therapeutic value of these drugs.

## **General principles**

The first step in the management of behavioral and psychological symptoms of dementia (BPSD) involves the careful assessment and correction of any physical, psychosocial or environmental triggers, or perpetuating factors, in the genesis of BPSD. The clinical presentation and diagnostic criteria for BPSD are presented in Module 2 and etiology is discussed in Module 3.

- 
- In general, non-pharmacological approaches are the first-line treatment for BPSD (see Module 5), but for symptoms that are moderate or severe, medication is indicated, often in conjunction with non-pharmacological interventions.
- 

When using drugs in a population with dementia, due consideration must be given to the age and disease-related changes in the pharmacokinetic and pharmacodynamic properties of the prescribed drug:

- Nutritional deficiencies in frail, elderly people can result in hypoalbuminemia leading to more of the active drug being available at the site of action
- Age-related changes in renal and hepatic function are associated with decreased drug metabolism and clearance and a greater chance of toxicity and side effects from drug-drug interactions
- The half-lives of psychotropics are further increased because most are lipophilic, and fat stores are increased in the elderly
- The brains of dementia patients are more sensitive than those of age-matched controls to the side effects of most drugs, particularly the sedating and cognitive-impairing effects of benzodiazepines, the central anticholinergic side effects of tricyclic antidepressants, and some neuroleptics.
- Many dementia patients, especially those with Lewy bodies, will demonstrate increased sensitivity to neuroleptic medication (conventional neuroleptics in particular), due to age and disease-related dopamine neuronal fallout.

Prescribing must be informed and judicious, utilizing low starting doses; slow and cautious dose titration, and careful monitoring for the emergence of side effects.

- 
- Before deciding whether to treat BPSD with medication, the following questions must be addressed:
    - Does the particular symptom or behavior warrant drug treatment, and why?
    - Is this symptom or behavior drug-responsive?
    - Which category of medication is most suitable for this symptom or behavior?
    - What are the predictable and potential side effects of a particular drug treatment?
    - How long should the treatment be continued?
- 

Drug treatment for BPSD should only be initiated after these symptoms have been found to:

- have no physical cause
- be unrelated to the effects of other medication
- not respond to or be appropriate for non-pharmacological interventions.

### ***Drug classes and target symptoms***

The issue of whether a particular drug is effective can be a difficult one. Pharmacological treatment is indicated, however, where there is evidence from practice that particular symptoms or behaviors respond to a drug intervention the use of different pharmacological agents in the management of BPSD is outlined in Table 1.

***Table 1. Pharmacological therapy and BPSD.***

<b>Drug category</b>	<b>Target symptom</b>
<b>Antipsychotics</b>	
Conventional neuroleptics	Psychosis (delusions, hallucinations), hostility, aggression, agitation, violent behavior, sleep-wake cycle disturbances
Newer antipsychotics	Psychosis (delusions, hallucinations), hostility, aggression, agitation, violent behavior, sleep-wake cycle disturbances
<b>Antidepressants</b>	
Trazodone	Sleep-wake cycle disturbances, agitation, aggression, anxiety, depressive syndromes
Selective serotonin reuptake inhibitors	Depressive syndromes, depression-associated agitation, emotionality, irritability
Tricyclic antidepressants	Depressive syndromes, depression-associated agitation, sleep disturbance, emotionality
Moclobemide	Depressive syndromes, depression-associated agitation
<b>Benzodiazepines</b>	Anxiety, agitation, tension, sleep disturbance
<b>Anticonvulsants</b>	Agitation, aggression, hostility, sleep-wake cycle disturbance, manic type behavior
Valproic acid, carbamazepine	

It is useful to identify the target symptoms or behaviors for a specific drug treatment because several symptoms can coexist in a single patient – a patient who is paranoid and aggressive may also be sleep disturbed and physically agitated. In this instance, a neuroleptic may be chosen to target the psychotic symptoms with secondary benefit for agitation and sleep disturbance.

As a matter of principle, drug treatment for BPSD should be time limited and, with the exception of antidepressant treatment for depression, should not exceed 12 weeks without a review of the treatment regimen. When medication is discontinued, however, it is possible that some patients will experience a recurrence of symptoms, in which case medication should be reinstated.

- 
- The outcome of a pharmacological treatment should be monitored on a routine basis for both its efficacy, i.e., effect on the frequency and severity of the symptom(s) and its side effects.
- 

## ***Antipsychotics***

There are two broad categories of neuroleptic medications available for use in dementia patients:

- Conventional neuroleptics are primarily dopamine D<sub>2</sub>-blockers and are associated with the development of extrapyramidal side effects (EPS). Examples of such agents are haloperidol, thiothixene and loxapine
- The second category is newer and is often referred to as novel or atypical as this class of agent is not typically associated with EPS. These agents have weak D<sub>2</sub>-blocking potential or, if they have D<sub>2</sub>-antagonist properties, these are balanced by serotonergic antagonist action.

Clozapine was the first and prototypical novel antipsychotic but there are now a number of agents available including risperidone, olanzapine, quetiapine and ziprasidone.

### Conventional neuroleptics

Traditionally, conventional neuroleptics are the most common psychotropic medication prescribed to agitated dementia patients in nursing homes and long-stay institutions (Ray et al., 1980; Gilleard et al., 1983). However, in spite of their widespread use only a modest evidence base exists to support such a trend. These drugs have been prescribed for a wide range of behavioral symptoms in dementia, sometimes without sufficient consideration given to which symptoms will respond to this class of medication and the impact of side effects.

Based on the evidence (Barnes et al., 1982; Petrie et al., 1982; Devanand et al., 1989; Finkel et al., 1995), the symptoms that appear to be most responsive to neuroleptic medications are:

- physical aggression and violent behaviors
- psychosis (hallucinations, delusions)
- hostility.

Individual patients with particular BPSD may show a beneficial response to neuroleptic medication and patients with distressing symptoms, other than these 'target symptoms or behaviors,' can benefit from an empirical trial of neuroleptic.

### Efficacy of conventional neuroleptics

There have been several uncontrolled studies and a few reports of placebo-controlled trials of the efficacy of conventional neuroleptics in dementia (Finkel et al, 1995; Devanand et al, 1998).

The uncontrolled studies are generally of short duration, i.e., 3-8 weeks, and include elderly patients with schizophrenia who might be expected to respond to neuroleptic treatment (Tewfik et al., 1970; Tobin et al., 1970). The improvement rate in such studies is 25-75%, but very few critical outcome measures were used.

Of the randomized, placebo-controlled trials of conventional neuroleptics in dementia patients, most had small numbers of patients and were of short duration. The consistent findings in these studies (Sunderland and Silver, 1988; Devanand, 1995) were:

- frequent occurrence of side effects
- a large placebo effect
- variable efficacy.

It is important to note that the early placebo-controlled studies evaluating efficacy in BPSD were carried out with conventional neuroleptics at higher doses than those currently used. However, Finkel, in a 20-week placebo-controlled crossover study found the drug was statistically significant. This might account for the high frequency of side effects reported, an argument supported by the much lower side effect rates reported in recent trials of conventional neuroleptics (Finkel et al., 1995). From an efficacy standpoint, a meta-analysis of such studies showed that conventional neuroleptics improved BPSD overall, but only in 18-26% more of patients compared with placebo (Schneider et al., 1990; Lanctot et al 1998). A recent placebo controlled study with haloperidol over 6 weeks showed significant benefit for haloperidol for psychosis and psychomotor agitation at higher doses of 2-3mg/day but not at lower doses of 0.5-0.75mg/day. A subgroup of patients on the higher dose of haloperidol developed significant extra pyramidal side effects (Devanand, DP et al., 1998).

### Side-effect profile of conventional neuroleptics

The most common side effects of conventional neuroleptics are:

- extrapyramidal side effects (e.g., drooling, rigidity, akinesia) with high-potency conventional agents such as haloperidol and thiothixene
- postural hypotension and anticholinergic side effects (e.g., dry mouth, constipation, blurred vision, urinary hesitancy and retention, increased confusion) with low-potency conventional agents such as thioridazine and chlorpromazine.

- 
- Dementia patients, because of their age and underlying degenerative brain disease are much more at risk of developing tardive dyskinesia.
- 

The estimated incidence of tardive dyskinesia in the elderly following conventional neuroleptic treatment is 30% per year. For this reason an 8-12 week (time-limited) exposure of dementia patients to neuroleptics is to be encouraged. When side effects occur, the dose of conventional neuroleptic should be reduced or discontinued depending on the severity of the adverse event, and an alternative agent considered. The use of anticholinergic agents to reverse the EPS of conventional neuroleptics should be avoided, as they are likely to increase cognitive impairment.

### Effects of conventional neuroleptics on cognition and function

It is possible that long-term exposure to conventional neuroleptics, while improving behavioral disturbance, results in a more rapid deterioration in functional ability and a progression of the stage of dementia. Treatment with haloperidol over 6–8 weeks was associated with a decline in cognition

on the Mini-Mental State Examination (MMSE) (Devenand et al., 1989). A number of studies have reported an association between the presence of psychosis or psychiatric symptoms and a more rapid rate of progression (McShane et al. 1997).

The association between psychosis and a more rapid downhill course could also be explained by a worsening of cognition and functional abilities with conventional neuroleptics (Stern et al., 1987; Chui et al., 1994; McShane et al., 1997). It has also been suggested that the worsening of cognitive impairment in patients with Alzheimer's disease could result through central muscarinic blockade caused by the anticholinergic side effects of low-potency conventional neuroleptics.

### **Withdrawal of conventional neuroleptics**

There are a number of studies to show that dementia patients' symptoms actually remain stable or improve when they are withdrawn from a conventional neuroleptic (Thapa et al., 1994; Horowitz et al., 1995; Bridges-Parlet et al., 1997). Thus, for some patients with disturbed behavior who are already on a conventional neuroleptic, withdrawing the medication may be a preferred option.

### **Reasons for limited efficacy of conventional neuroleptics in BPSD**

The limited efficacy of conventional neuroleptics in treating BPSD (only 18-26% improvement vs. placebo in two meta-analyses; Schneider et al., 1990; Lanctot et al, 1998) may have several explanations:

- Psychosis in dementia may have a different neurobiological substrate from functional illness and therefore, may be less responsive to neuroleptics.
- Some psychotic symptoms in dementia (such as delusions of stealing and misidentifications) may be directly related to cognitive and perceptual abnormalities.
- People with dementia are elderly; therefore use of conventional neuroleptics is limited by the patient's sensitivity to side effects. Only low (and hence, less effective) doses can be used.

### **Newer antipsychotics**

There are open-label studies, case reports and recent reports from four placebo-controlled, double-blind studies to suggest that newer antipsychotics are effective in the treatment of BPSD and have improved side-effect profiles.

It has been suggested that newer antipsychotics, because of their lower propensity to cause EPS, may be less likely to cause tardive dyskinesia. However, a definitive statement to this effect will require long-term treatment studies.

### **Side-effect profile of newer antipsychotics**

With the exception of clozapine (the utility of which is limited in BPSD by its side effects), the side-effect profile of newer antipsychotics is generally favorable.

Clozapine has significant anticholinergic and postural hypotensive effects, but it is associated with a risk of agranulocytosis and requires weekly white cell count monitoring. There is some evidence to suggest that olanzapine, like clozapine, has anticholinergic side effects. Risperidone can be associated with the emergence of EPS, postural hypotension, and sedation at higher doses. Specifically in the treatment of BPSD, there are no current data from controlled studies on the safety of neuroleptic agents other than risperidone and olanzapine. Studies with quetiapine are ongoing.

### **Efficacy of newer antipsychotics**

Data are currently available for risperidone and olanzapine in dementia patients with BPSD. In one open-label study, 83% of patients with BPSD taking 0.5–1.0 mg/day risperidone showed an improvement in symptoms (Goldberg and Goldberg, 1995). This same study showed that

risperidone is able to produce an improvement in sleep quality--82% of patients reported better sleep quality and 63% reported that they were more awake during the day.

To date, three large multicenter trials of risperidone for BPSD have been conducted. Risperidone at a dose of approximately 1 mg/day has been found to be superior to placebo in the treatment of BPSD, particularly for aggressive behaviors in dementia patients and for psychotic symptoms. Risperidone at this dose is well tolerated and has an EPS profile similar to placebo (De Deyn, 1997; Katz, 1999, Brodaty et al, 2001, Alzheimer's Disease International Conference, Christchurch, October 2001).

A multicenter nursing home study of olanzapine in BPSD has shown that 5 and 10 mg/day doses of olanzapine was significantly superior to placebo and well tolerated in treating agitation/aggression. Curiously the 5mg dose showed greater efficacy than the 10mg dose (Street et al., 2000).

### **Dementia with Lewy bodies: considerations**

Dementia with Lewy bodies can be a relatively common clinical problem. It has been observed in approximately 15% of dementia patients at autopsy. Patients often have prominent visual hallucinations and psychotic symptoms and are likely to be treated with neuroleptics. Severe and sometimes fatal sensitivity to conventional neuroleptics has been described in dementia with Lewy bodies (McKeith et al., 1995).

Evidence for the use of neuroleptics in dementia with Lewy bodies has generally come from retrospective chart reviews, and not from placebo-controlled clinical trials. The current recommendations are that patients who are suspected of having dementia with Lewy bodies should not be prescribed conventional neuroleptics.

Reports on the tolerance to novel antipsychotics such as risperidone in patients with dementia with Lewy bodies have been both positive and negative (Lee et al., 1994; Allen et al., 1995; McKeith et al., 1995). For severe BPSD, low doses of the newer antipsychotics, e.g., risperidone 0.25 mg, clozapine 6.25 mg, olanzapine 2.5 mg, or quetiapine 25mg could be used, but patients must be monitored very carefully in a day hospital or inpatient setting for treatment-emergent neuroleptic sensitivity.

### **Guidelines for prescribing**

On the basis of evidence from the literature, the following clinical guidelines for the use of neuroleptics are recommended:

- Only treat moderate to severe BPSD.
- Try non-pharmacological methods first, then in conjunction with medication.
- Try to target specific symptoms: physical aggression, hallucinations and delusions.
- Check for a history of neuroleptic sensitivity and consider the diagnosis of dementia with Lewy bodies before prescribing any neuroleptic.
- Consider discontinuing neuroleptics in patients with BPSD before automatically switching to a different class of neuroleptic or increasing the dosage.
- Start with low dosages and go slowly when using neuroleptic medication. (See Table 2 for suggested dosage schedules.) A starting dose for a conventional neuroleptic would be 0.5 mg/day, and a maximum dose would be 2 mg/day haloperidol equivalents. The dosing range for risperidone is 0.5 mg/day to 2 mg/day with optimum dose of 1.0 mg/day (Brecher, 1997; De Deyn, 1999; Katz et al, 1999; Brodaty et al, 2001) allowing at least 2 days before the initial dose escalation. For olanzapine the dosage range would be 2.5mg-10mg, and for quetiapine 25-150 mg.

- Since newer antipsychotics are better tolerated than the older conventional agents the neuroleptic must be tailored to the individual patient. The choice of agents depends more on the likely side effects than differential efficacy.
- Watch closely for treatment-emergent side effects. Avoid or minimize side effects of EPS, postural hypotension, anticholinergic side effects, sedation, by slow titration and low doses.
- Set duration for treatment and monitor outcome. A time limit of 12 weeks' treatment is recommended and should be reviewed during and after. If a 4-6-week trial of one agent at an adequate dose fails to decrease the frequency, severity or impact of a target symptom, the trial of a second agent would be indicated.

**Table 2. Clinical recommendations for dosing of conventional neuroleptics and newer antipsychotics in the treatment of BPSD.**

Drug	Start (mg)	Dose range (mg)	Schedule
Haloperidol	0.5	0.5–2	Once daily
Thiothixene	1	1–10	Once daily
Risperidone	0.5	0.5–2	Once daily
Clozapine*	6.25	10–100	Twice or once daily
Olanzapine.	2.5	5–10	Once daily
Quetiapine*	25	25-150	Divided dose

\*No double blind, placebo-controlled data available

## **Anxiolytics**

### **Benzodiazepines**

After neuroleptics, benzodiazepines are the second most frequently used agents in the treatment of BPSD. Benzodiazepines are used clinically primarily for 'agitated behaviors' and sleep disturbance in dementia patients. A number of controlled studies have shown that benzodiazepines decrease agitated behaviors compared with placebo to the same extent as conventional neuroleptics (Chesrow et al., 1965; Kirven and Montero, 1973; Covington, 1975; Coccaro et al., 1990).

BPSD that respond best to benzodiazepines include:

- anxiety
- tension
- irritability
- insomnia

Side effects are common and most often include excessive sedation (drowsiness), ataxia, amnesia, and confusion. In addition, the risk of falls in dementia patients is increased with benzodiazepines, particularly the long-acting agents that accumulate over time (Grad, 1995).

Short-acting benzodiazepines such as oxazepam or lorazepam that do not accumulate are preferred, and are most effective if used for short periods, i.e., a few weeks (Sanders, 1965). Low doses, e.g., lorazepam 0.5–2.0 benzodiazepine equivalents mg/day should be used for a time-limited period. Lorazepam may be especially useful as a premedication for episodic disturbance or where agitation or distress can be anticipated (e.g., minor surgical procedures or dental visits).

After patients have been maintained on benzodiazepines for over 4–6 weeks, a gradual taper is advised prior to discontinuation.

## **Buspirone**

Buspirone is a serotonin 5-HT<sub>1a</sub> partial agonist, that in case reports, and open studies have been found to be helpful in agitated dementia patients. However, in a placebo-controlled study (at doses of 30 mg/day), buspirone was very well tolerated, but had no beneficial effect on agitation (Lawlor et al., 1994). In a multicenter study performed in the USA, no positive results have been reported.

On the basis of the available data, buspirone cannot be recommended routinely for moderate to severe BPSD, but may have a role in the management of mild anxiety in dementia patients at doses of 20-60 mg/day.

## **Anticonvulsants**

Both open-label and controlled evidence is accumulating for the efficacy of anticonvulsants for agitated behaviors in dementia. In general, anticonvulsants are well tolerated and produce little toxicity compared with conventional neuroleptics. They are being used increasingly in the treatment of some BPSD.

### **Carbamazepine**

Carbamazepine (usual dose range 300–800 mg/day) has been used in patients with agitation secondary to brain damage and is increasingly being prescribed to patients with BPSD. Several case reports, open trials (Essa, 1986; Leibovici and Tariot, 1988; Patterson, 1988; Gleason and Schneider, 1990; Lemke and Stuhlmann, 1994) and double-blind trials (Tariot et al., 1994; 1998) support the efficacy of carbamazepine to treat agitation in BPSD.

In two of the controlled trials, doses of up to 300 mg/day were well tolerated by frail elderly patients. Small, placebo-controlled studies of doses up to 600 mg/day have also shown positive effects (Cooney et al., 1996). Another open study suggested that carbamazepine augmentation of a conventional neuroleptic was helpful in agitated dementia patients (Lemke, 1995).

The side effects of carbamazepine include sedation, skin rash, headache, leucopenia and mild elevation of liver function tests.

### **Valproic acid**

Valproic acid is available in several forms, including the well-tolerated divalproex sodium formulation that minimizes gastrointestinal distress. The results from clinical trials for bipolar disorder, open trials in patients with dementia (Mellow et al., 1993; Lott et al., 1995), and a single placebo controlled study show that valproate demonstrates similar efficacy to carbamazepine; however, data from further controlled trials are awaited. The usual dose range for valproic acid is 400–1000 mg/day (Porsteinsson et al., 2001).

Compared with carbamazepine, valproic acid has a significantly reduced potential for drug-drug interactions and side effects. But, it has been associated with sedation, diarrhea, tremor, nausea, weight gain, hair loss and abnormal liver function.

## **Antidepressants**

### **Trazodone**

In keeping with the serotonin hypothesis for AD (Lawlor, 1990), open studies and some controlled trials support the use of trazodone for agitation in patients with BPSD (Pinner and Rich, 1988; Aisen et al., 1993; Lawlor et al., 1994; Sultzer et al., 1997). Trazodone has sedative properties and thus may also be useful in treating sleep disturbance in dementia.

Doses varying from 50–600 mg/day have been used, although the recommended dose range for patients with severe BPSD would generally not exceed 200–300 mg/day. The main side effects of trazodone are:

- somnolence
- postural hypotension.

### **Tricyclic antidepressants**

There is much anecdotal evidence supporting the use of tricyclic antidepressants in depressed dementia patients (Reynolds et al., 1987). There is, however, only one placebo-controlled trial evaluating the beneficial effects of a tricyclic antidepressant in depressed dementia patients and this study found a significant benefit for both drug and placebo (Reifler et al., 1986).

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- Tricyclic antidepressants are associated with problematic and frequent side effects in dementia patients and must be used with caution.
- 

The most common side effects associated with tricyclic antidepressants are postural hypotension, blurred vision, urinary hesitancy and intracardiac conduction defects. If tricyclic antidepressants are to be used in depressed dementia patients, secondary (e.g., nortriptyline, desipramine, lofepramine) rather than tertiary amines (e.g., amitriptyline, dothiepin) are preferred, due to better tolerability.

### **Selective serotonin reuptake inhibitors**

There is mainly open experience with selective serotonin reuptake inhibitors in depressed demented patients with the suggestion that they improve depressed mood and are well tolerated (Burke et al., 1994).

There have been some indications that dementia patients, particularly those with associated extrapyramidal syndromes, may be more likely to develop EPS (Gormley et al., 1997). Two placebo-controlled trials of selective serotonin reuptake inhibitors (citalopram 10–30 mg/day) in elderly patients, with and without dementia, who had depression requiring treatment found significant improvements in depression, emotionality, anxiety, agitation and social interaction on citalopram compared with placebo (Nyth and Gottfries, 1990; Gottfries et al., 1992).

A recent retrospective review of studies evaluating selective serotonin reuptake inhibitors in patients with depression and psychosis complicating dementia showed a significant effect on both psychosis and depression, suggesting that these agents could have antipsychotic potential in dementia patients (Burke et al., 1997). However, this preliminary finding must be tested further in double-blind controlled studies.

Side effects of selective serotonin reuptake inhibitors are generally less common and severe than those of tricyclic antidepressants but include:

- gastrointestinal symptoms (e.g., nausea, vomiting)
- akathisia
- restlessness
- insomnia
- weight loss
- hyponatremia.

### **Other antidepressants used in depressed dementia patients**

When an antidepressant is selected, overall tolerability as well as favorable effects on anxiety, sleep disturbance and agitation should also be considered. Two recently introduced antidepressants, mirtazepine and nefazodone, share these properties and can be considered promising candidates for use in depressed patients with dementia. Both are proven to be effective and safe in elderly patients.

A number of placebo-controlled trials carried out with antidepressants that are not available in the USA and some European countries, namely, maprotiline and minaprine have indicated that depressed dementia patients respond to antidepressants (Passeri et al., 1987; Fuchs et al., 1993).

Other agents such as moclobemide, a reversible inhibitor of monoamine oxidase A, at doses of 150–600 mg/day have a proven favorable side-effect profile in elderly dementia patients and can be useful in the treatment of depression. One study demonstrated it was effective in the treatment of depression in dementia (Roth M et al., 1996).

### **Antidepressant dosing recommendations**

If an antidepressant is to be prescribed, selective serotonin reuptake inhibitors or secondary amine tricyclic antidepressants should be used. Doses should start low and be increased gradually. A dosing schedule for selected antidepressants is shown in Table 3. Patients should be treated for a time-limited period of 6 months at a time and do not need to be maintained on antidepressants indefinitely, since many of the depressions remit within a 12-month period (Brodaty and Luscombe, 1996).

**Table 3. Dosing schedule for selected antidepressants in patients with dementia.**

<b>Drug</b>	<b>Initial dose (mg/day)</b>	<b>Target dose (mg/day)</b>
Paroxetine	10	20–30
Fluoxetine	10	20–30
Sertraline	25	50–100
Nortriptyline	10	20–60
Moclobemide	150	150–600
Mirtazepine	15	15–45

### **Miscellaneous drug classes**

#### **Cholinesterase inhibitors**

Cholinesterase inhibitors (such as tetrahydroaminoacridine or tacrine, donepezil hydrochloride, rivastigmine and galantamine) are only licensed for the treatment of cognitive symptoms in Alzheimer's disease. There is some evidence, however, that cholinergic drugs may have beneficial effects on BPSD, particularly apathy, hallucinations and delusions, anxiety and depression (Kaufer et al., 1996; Feldman 2001; Blesa R. 2000; Scott and Goa, 2000).

Cholinergic drugs may even decrease the emergence of BPSD (Tariot et al 2000). A placebo-controlled study in DLB has demonstrated efficacy for rivastigmine in the treatment of hallucinations, delusions, apathy and anxiety. Not all studies have demonstrated a benefit on BPSD with cholinesterase inhibitors (Fillit et al, 2000), and not all BPSD benefit from their use. The use of this class of drugs may depend on the nature of the behavioral disturbance and the stage of the dementia.

### **Lithium**

Published data on the use of lithium in BPSD are limited and there are no controlled studies of its use. One open study (Williams and Goldstein, 1979) reported decreased agitation in six out of eight patients with mixed chronic brain syndromes, but another reported little benefit and prominent toxicity (Randels et al., 1984). Thus, there seems to be no reason to use lithium to treat BPSD given its toxicity in this patient group and the lack of data showing any therapeutic effect.

### **$\beta$ -Blockers**

There have been only two reports, both uncontrolled, of  $\beta$ -blockers in dementia, which found some benefit (Petrie and Ban, 1981; Weiler et al., 1986). The only controlled studies with propranolol (40–400 mg) and pindolol (10–40 mg) have been in brain injury patients (Greendyke et al., 1989). Thus, there is no evidence on which to base a recommendation for the use of  $\beta$ -blockers in BPSD.

### **Selegiline**

Selegiline is an irreversible inhibitor of monoamine oxidase B at low doses. It has been suggested that decreasing or normalizing monoamine oxidase B activity in Alzheimer's disease might result in asymptomatic improvement in this illness (Tariot et al., 1987).

The results to date with selegiline in the treatment of BPSD in Alzheimer's disease have been mixed. Some small, open-label studies have shown beneficial effects on BPSD (Goad et al., 1991; Schneider et al., 1991), but the largest and most recent placebo-controlled study showed no effect of selegiline treatment (Burke et al., 1993). The dementia patients in this last study did not exhibit BPSD; therefore, it was unlikely that a treatment effect would be seen. In a study of Alzheimer's disease patients with depression and agitation, selegiline has been shown to improve BPSD, although the effect size was small (Lawlor et al., 1997).

The evidence for selegiline in BPSD is generally positive for minor depressive symptoms associated with withdrawn behavior or agitation. Side effects are infrequent with the usual dose of 10 mg/day and include postural hypotension. There are no dietary restrictions while the dose is maintained at 10 mg/day.

### **Sedative hypnotics**

There are no specific studies of pharmacological treatment of sleep disturbance in dementia patients and there is therefore little evidence to guide practice.

In general, agents with short-to-intermediate half-lives and few active metabolites are to be favored (e.g., zopiclone 3.75–7.5 mg, zolpidem 5–10 mg, lorazepam 0.5–1.0 mg, oxazepam 7.5–15 mg, temazepam 10 mg). Sedative hypnotics should only be used for the short-term management of sleep disturbance in BPSD. When long-term treatment is necessary, an alternative agent with sleep-enhancing properties such as trazodone (50–150 mg nocte) may be useful.

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- Where sleep disturbance is part of depression or psychotic behavior, an antidepressant or antipsychotic should be the drug of choice.
- 

### ***Electroconvulsive therapy for depression in dementia***

In the management of depression in patients with dementia, electroconvulsive therapy (ECT) may be an option in the management of severe depression complicating dementia. There are three important issues to be addressed when considering whether ECT should be given:

- making the diagnosis of depression in the face of dementia
- excluding medical causes of depression (e.g., UTI)
- the efficacy of ECT in depressed dementia patients
- potential side effects of ECT in the depressed patient with pre-existing cognitive impairment.

The obvious concern when using ECT with dementia patients is the risk of increased cognitive impairment after ECT. Increasing the time interval between treatments can reduce this risk. Less cognitive impairment would be expected if unilateral treatment were used, but balanced against this is the need for more sessions with unilateral treatment compared with bilateral.

The issue of competency to give informed consent for ECT in a dementia patient is a difficult one. Even in patients with mild dementia it is advisable to obtain the consent of the next of kin. Patients should be taken off all psychotropics during the course of ECT to decrease the likelihood of post-ECT confusion. After the course of ECT (usually 6–8 treatments), patients should receive prophylactic treatment with antidepressants for 6–9 months, and possibly longer if there is a history of previous episodes.

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# Behavioral and Psychological Symptoms of Dementia (BPSD) Educational Pack



The BPSD Educational Pack was produced by the International Psychogeriatric Association (IPA) under an educational grant provided by Janssen-Cilag. The opinions expressed in the BPSD Educational Pack are those of the contributing authors and are not to be construed as the opinions or recommendations of the publishers or sponsors. Full prescribing information must be obtained for any of the drugs or procedures discussed herein.

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There are changes occurring in India too. The Alzheimer’s and Related Disorders Society of India (ARDSI) with many chapters all over India has, to some extent, succeeded in increasing the level of awareness about dementia. The plight of the families who look after relatives with dementia at home is being recognized and discussed. Specialized dementia care services, which focus on the management of BPSD, are likely to come up in many general hospitals which are usually located in the urban areas. This is primarily because of increasing demand for such services from the educated sections of the society. In addition, the availability of many drugs useful in the management of BPSD has brightened the prospect of better management of these symptoms. The prospect of networking centers that provide specialized dementia care is also being discussed. It is anticipated that abundant information about the management of BPSD will be available in the next few years, once specialized dementia care services are established in many general hospitals in India. ....	18
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## **Preface**

Cognitive symptoms of dementia have been those most widely studied. Recent years have seen the growth of research in functional changes in persons with dementia, including reduced ability to carry out normal activities of daily living. This series of educational modules concentrates on the behavioral and psychological symptoms of dementia (BPSD), which have historically been referred to as 'behavioral disturbances'.

BPSD exact a high price from both the person with dementia and the caregiver in terms of the distress and disability they cause if left untreated. This is the key to the development of this Educational Pack. We believe that BPSD are recognizable, understandable and treatable. The recognition and appropriate management of BPSD are important factors in improving our care of dementia patients and their caregivers.

This BPSD Educational Pack originally distributed in 1998 and updated in 2002 draws on material presented at the Consensus Conferences of the International Psychogeriatric Association (IPA) Task Force on Behavioral Disturbances of Dementia (now the IPA Task Force on Behavioral and Psychological Symptoms of Dementia), held in the Spring of 1996 and the BPSD Update Conference in 1999. Until recently research on the recognition and treatment of BPSD has been sparse. The consensus conferences effectively took the first steps towards recognizing BPSD as a collection of core symptoms of dementia.

Regulatory agencies of several countries recognize BPSD as a legitimate entity for treatment and research purposes. Others have approved research and treatment for specific components, such as psychosis of Alzheimer's disease.

We hope these modules will provide a useful overview of the presentation and causes of BPSD, offering constructive guidance on treatment interventions, both pharmacological and non-pharmacological, coupled with information on caregiver education and support. We suggest that readers make use of the reference and recommended reading lists provided at the end of each module.

Also, we hope the material will contribute to the improved management of dementia patients with BPSD and reduce some of the stresses experienced by the caregiver and families of dementia patients.

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## **Key messages**

- Studying behavioral and psychological symptoms of dementia (BPSD) across cultures allows the identification of similarities and differences that may be useful to determine the best approach to managing these symptoms in different populations.
- An effective approach to management in one culture may not necessarily work in another, given the different prevalence of various BPSD and level of tolerance for these within that culture.
- The patient's and caregiver's location can affect the impact and subsequent management of BPSD. Symptoms that pose difficulties in an urban setting (such as pacing or wandering) may not be regarded as problematic in a rural setting (where most patients will have room to pace and are less vulnerable if they wander).
- Comorbid conditions such as schizophrenia, depression and alcoholism may vary in frequency across communities and could alter the presentation of BPSD in demented subjects.

## **Introduction**

This module reviews cross-cultural and transnational aspects of BPSD and gives a series of snapshots from different ethnic groups, cultures and nations around the world. It begins with a discussion of aspects of BPSD likely to vary across cultures and examines the reasons behind real or apparent differences. Each of the cross-cultural perspectives comes from physicians who all understand the culture described.

Dementia and associated BPSD are already recognized as a major medical challenge for the aging populations of the Western world. Although in many developing countries, BPSD are not yet regarded as a central focus, there is no doubt that, in time, these symptoms will present a management issue for these countries. The groundwork in observing similarities and differences in dementia and BPSD across cultures discussed herein will likely prove valuable in the future.

### **Aspects of BPSD likely to vary across cultures**

The study of BPSD across cultures and nations allows the identification of similarities and differences to determine the best approach to management. However, it is possible that an effective approach to management in one culture may not necessarily work in another given the varying levels of prevalence and tolerance of BPSD within the communities in which they occur.

In the following section, cultural factors critical to our understanding of the prevalence and presentation of BPSD and its assessment and management will be reviewed. Further, the impact of research methodology on our understanding of these areas will be evaluated. Lastly, cross-cultural perspectives pertaining to BPSD in USA, Turkey, India, Argentina, Taiwan, Africa and the Caribbean will be highlighted.

## **Prevalence and presentation**

Prevalence and presentation of BPSD in different communities are affected by a variety of illness-related and cultural factors. Illness-related factors include the rates of dementing disorders in the community and the expected life span. In some African and Asian countries the lifespan of the general population is shorter than in some Western countries. Thus, patients with dementia are also likely to have a shorter life expectancy. This lessened life span may influence:

- the development of BPSD; and,
- caregiver perceptions of the severity of symptoms.

In addition to prevalence and survival rates, BPSD may vary according to the predominant dementia subtype(s) found in the community. The co-morbid conditions of schizophrenia, depression and alcoholism may also vary in frequency across communities and could alter the presentation of BPSD in persons with dementia.

Cultural-related factors may also influence the prevalence and presentation of BPSD. In some countries, caregivers deny BPSD to avoid the stigma of mental illness. This is particularly seen in countries such as Nigeria and Argentina,

Although it is important to evaluate the cultural factors among various countries, it is important to recognize the cultural variations within a country. In the section on Argentina, the authors report a mixture of ethnic cultures. In Buenos Aires, for example, caregivers are more apt to inquire about BPSD treatment. Argentineans descending from the Volga region of Germany, in comparison, are more likely to deny BPSD as these symptoms are stigmatizing. Additionally, in many studies examining neuropsychiatric symptoms among black patients with dementia in the United States, black populations are treated as homogeneous groups (Cohen and Magai, 1999). This is problematic due to intraracial differences in psychiatric symptom expression (Cohen and Magai, 1999). Therefore, it is important to consider the possibility of intraracial differences when making comparisons about the prevalence and presentation of BPSD.

Table 1 (below) documents the frequency of BPSD in the European Union (Homma, 1996), the United States (Reisberg et al., 1989; Patterson et al., 1990) and Japan (Karasawa et al., 1988). Probably one of the most remarkable differences is the frequency of depressive symptoms between the United States, the European Union, and Japan. This may be explained in part by the different attitudes of health professionals, including physicians, toward the depressive complaints of the elderly with dementia. For instance, in Japan, widows or widowers sometimes complain “Last month, I finished the seventh anniversary ceremony of the death of my husband/wife. So it may be good timing to terminate my life.” Such a complaint may be recognized as a depressive symptom in the United States or Europe, but, in Japan this type of statement is not unusual, and is usually not recognized as a symptom of depression.

**Table 1. Frequency (%) of BPSD in AD in the European Union, USA, Japan and Turkey. adapted from Homma, 1996.**

	European				
	Union	US	US	Japan	Turkey
Symptoms in BEHAVE-AD	(n=38)	(n=91)	(n=34)	(n=92)	(n=36)
Paranoid and delusional ideation	57.9		38	20.0	29.3
‘Others are stealing things’	13.2	22.0	21		22.9
‘Residence is not home’	31.6	17.6	15		25.5
‘Spouse is an imposter’	10.5	14.3	0		5.2
Delusion of abandonment	21.1	11.0	---		13.7
Delusion of infidelity	---	---	0		15.3
Suspiciousness	10.5	29.7	18	17.4	49.5
Delusions other than above	18.4	19.8	–		26.5

Hallucinations	21.1		7.6	7.6	
Visual hallucinations	18.4	14.3	15		25.1
Auditory hallucinations	–	–	–		5.9
Olfactory hallucinations	–	–		–	–
Haptic hallucinations	–	–		–	2.9
Other	–	–		–	–
Activity disturbances	86.8		44		
Wandering	57.9	28.6	12	21.7	49.8
Purposeless activity	57.9	47.3	42		41.3
Inappropriate activity	57.9	33.3	19	27.2	80.2
Aggressiveness	84.2			18.5	
Verbal outburst	60.5	29.7	24	7.6	46.4
Physical threats and/or violence	47.4	16.5	–	10.9	29.2
Agitation other than above	50.0	40.7	12		35.6
Diurnal rhythm disturbances	42.1		13	21.7	
Day/night disturbances	42.1	25.3	13		44.2
Affective disturbances	28.9		32	2.2	
Tearfulness	26.3	37.4	32		24.8
Depressed mood: other	13.2	26.4	0		28.1
Anxieties and phobias	36.8		50	–	
Anxiety about upcoming events	10.5	27.4	41		21.3
Other anxieties	10.5	22.0	26	5.4	37.0
Fear of being alone	21.1	25.3	15		38.6
Other phobias	–	13.2	12		–

### Approaches to Assessment

Evaluation of behavioral disorders in elderly patients with dementia poses some specific problems when working in different cultural settings. It is important to note the following critical factors when making comparisons across cultures:

- Awareness of the significance of BPSD
- Level of expertise in assessment of BPSD
- Tolerance of specific behavioral and psychological symptoms
- Cultural appropriateness of rating scales

In many countries, such as Turkey and India, dementia and BPSD are perceived as a national consequence of aging. As a result, caregivers may not even seek assessment of the symptoms unless these symptoms are deemed severe. In some cultures, Turkey for example, psychiatrists and general practitioners may lack the expertise to assess BPSD. It is important to note, however, that some countries highlighted in this module have made a concerted effort to promote the awareness of dementia over the last few years. For example, as Alzheimer's organizations are becoming more active in many areas of the world such as India and Mexico, the awareness of dementia is heightened and caregivers are finding outlets to discuss dementia.

In the United States, efforts are also being made to increase the awareness of BPSD and refine criteria of syndromes in AD. For example, Jeste and Finkel defined criteria for a distinct syndrome, psychosis of AD (Jeste and Finkel, 2000). Consequently, psychosis of AD has been accepted by the Federal Drug Administration as a target for intervention (Olin et al, 2002). Further, researchers in the United States have also developed provisional diagnostic criteria for depression of

Alzheimer's disease (Olin et al, 2002). Developing specific criteria for such conditions as psychosis and depression of AD has the following implications:

- reduction of heterogeneous diagnostic methods
- generation of homogenous populations in research studies
- increased clinician recognition of the conditions

The tolerance of specific BPSD also differs across cultures. Although wandering may be considered an important focus in the management of dementia in the United States, it was not considered a problem in India until recently. Incontinence, however, has been noted in the literature to be of concern since there is a high expectation of a certain level of personal hygiene in India (Chandra, 1996).

Rating scales are an important means to assessing BPSD. Yet, if cross-cultural comparisons are to be made, these rating scales must be compatible across cultures. Most rating scales involve observations of symptoms by key informants, usually spouses. This is probably a reasonable way to proceed within one culture or one defined population as informants' views about what constitutes acceptable behavior or disruptive symptoms are likely to be somewhat similar. This may not hold across cultures, however, where tolerance of behaviors and understanding and expectations of the elderly may vary widely. To ensure validity in the assessment of BPSD, rating scales need to include some measurement of informant personality characteristics including tolerance of disruptive behavior and views on the role of the elderly.

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- Rating scales need to be translated into local languages. Further, the scales should be 'harmonized' – the instruments must be consistent with the cultural, linguistic and educational norms of the subject population.
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Prior to the development of local language versions of rating scales, the clinical terms included in the scales should be clearly defined. For example, the definition of agitation used in the CMAI is somewhat different from that in Japan where physically abusive behaviors are usually not included in agitation. In Japan, agitation means behaviors with restlessness and irritable mood.

Rating scales that can be applied with validity in different cultures have been developed. For example, the Composite International Diagnostic Interview (CIDI), a World Health Organization (WHO)-sponsored international epidemiologic interview, and an expansion of the Diagnostic Interview Schedule (DIS), has now been tested in worldwide field trials.

There are now reliable screening instruments to identify dementia based upon cognitive performance. Some of these, like the Hindi Mental State Exam and the Cognitive Abilities Screening Instrument (CASI), have been used successfully in cross-cultural studies. One assessment scale, the Community Screening Instrument for Dementia (CSID) has been developed to include both cognitive testing and informant data about performance in everyday living. This instrument has now been used with good sensitivity and specificity in the Cree (Native American), African-American, Chinese and Yoruba (Nigerian) populations.

Clinical assessment instruments based upon translations of the Consortium to Establish a Registry in Alzheimer's Disease (CERAD) neuropsychological battery, the Geriatric Mental Status (GMS), and the Cambridge Examination for Mental Disorders of the Elderly (CAMDEX) are also available. There are now several internationally-used rating scales available in Asian countries (Homma 2000). The NPI has been used to assess BPSD in United States, Taiwan, Japan, and Italy. More recently, the NPI has been used in demented patients from Yoruba, Nigeria, after being translated, back translated and harmonized into Yoruba (Baiyewu et al, 2002)

In their pilot study, the 10/66 Dementia Research Group made an attempt to develop a one-stage screening procedure for dementia in the community. They interviewed 2,885 persons aged 60 and over in 25 centers in India, China and South East Asia, Latin America and the Caribbean and Africa; 729 people with dementia, and three groups free of dementia; 702 with depression, 694 with high education and 760 with low education. Experienced local clinicians diagnosed dementia (DSM-IV dementia and Clinical Dementia Rating mild or moderate) and depression (Montgomery Asberg Depression Rating Scale 18 or over). The Geriatric Mental State, the Community Screening Instrument for Dementia and the modified CERAD 10 word list-learning task were then administered by an interviewer, masked to case status.

Each measure independently predicted dementia diagnosis. In a split-half procedure, an algorithm derived from all three performed better than any of them individually; applied to the other half of the sample it identified 94% of dementia cases with false positive rates of 15%, 3% and 6% in the depression, high education and low education groups. The algorithm developed and tested by the 10/66 provides a sound basis for culture and education-fair dementia diagnosis in clinical and population-based research, supported by translations of its constituent measures into many languages, covering the majority of the peoples of the developing world.

When we conduct cross-cultural comparative studies, there is no doubt that rating scales employed in the study should be harmonized from the view point of different ethnic backgrounds as stated earlier. However, one of the more sensitive problems for most health professionals is how to choose an appropriate rating scale for the study or their daily activities in the community or facilities. Neville and Byrne (2001) reviewed 31 rating scales used to measure BPSD. They identified five which are recognized as suitable for use by nurses:

- Cohen-Mansfield Agitation Inventory (CMAI)
- Dementia Behavior Disturbance Scale (DBDS)
- Nursing Home Behavior Problem Scale (NHBPS)
- Pittsburg Agitation Scale (PAS)
- Revised Memory Behavior Problem Checklist (RMBPC)

The Neville and Byrne review did not have a cross-cultural aim. However, it seems that the results of this review could be helpful in determining a rating scale that would be appropriate to the specific goals of a study. A cross-cultural or trans-national study is needed to promote and facilitate cross-cultural comparative studies on BPSD.

### **Approaches to Management**

Reactions to BPSD and subsequent management approaches vary across different communities depending upon:

- size and location of the community
- availability of caregivers, and presence or absence of extended family
- availability of healthcare services
- availability of nursing homes
- role and expectations of the elderly
- concepts of dementia and deviant behavior
- tolerance of BPSD in the community.

General statements from cross-cultural perspectives regarding management include the following:

In the United States and Jamaica, combination therapies such as non-pharmacological management with pharmacotherapy are often utilized. Atypical neuroleptics, antidepressants, mood stabilizers, and anxiolytics are used in the management of BPSD in the USA and Jamaica. Similarly, pharmacological management is also used for the treatment of BPSD in Turkey and

Mexico. Neuroleptic use in Turkey and Mexico, however, is mostly with traditional neuroleptics. In the rare instances that demented patients from Ibadan, Nigeria, receive treatment for BPSD, phenothiazines are prescribed.

Nursing home care is available for patients with dementia, with and without severe BPSD, in many countries like the United States and Argentina. However, in these countries, most patients with dementia reside at home with their family. In the United States, Caucasians utilize more nursing home beds compared to African-Americans. In Turkey, patients with dementia reside mostly in their homes, while care in a specialized unit is reserved for those patients with severe BPSD. Nursing home care is not available in India and Nigeria. Consequently, those with severe BPSD in India and Nigeria are cared for by family.

### **Research methodological considerations**

Researchers must be careful about making assumptions about the prevalence or presentation of BPSD across cultures, as well as management and treatment of BPSD, due to a number of methodological factors (Arai, 2000; Jeste and Finkel, 2000; Cohen and Magai, 1999; Discussion 7, 1996; Valle, 1994; Wragg and Jeste, 1989). Some specific examples include the following:

- It is important to note the comparability (or lack thereof) of the populations studied. In western cultures, for example, rates for populations of convenience such as nursing home residents or outpatients are often used (Discussion 7, 1996). Likewise, are the groups that are being compared similar in their dementia severity with regard to type of dementia, methods of assessment, etc.? Furthermore, are these factors clearly defined?
- Many studies of BPSD do not provide a racial composition of the population studied, or test for racial differences (Cohen and Magai, 1999).
- Much of the literature available from various countries is via studies with small sample sizes. More data from large representative samples is needed for useful comparisons.

### ***Cross-cultural perspectives***

#### **BPSD in the USA**

The presence of Alzheimer's disease (AD) and other dementing disorders in different ethnic groups in the United States is well-documented. However, the characteristics of dementing disorders, such as the presence of BPSD, remain largely unexplored in these groups. This is quite troublesome, in light of the diverse aging population.

According to the US Census, approximately 35 million people aged 65 or older resided in the United States in 2000, representing 12 percent of the population (US Census Bureau, 2000). The elderly have increased in growth since 1900 when they represented only 4 percent of the population (Federal Interagency Forum, 2000). Although there has been considerable growth in the elderly in the United States, older persons represent 15 percent or more of the total population in other industrialized countries. By 2050, the elderly population is projected to more than double to 80 million (US Census Bureau, 2001).

The "oldest old", representing those aged 85 and older, is the fastest growing segment of the elderly population. Representing approximately 4 million people in 2000 (two percent of the US population), it is projected that this group will increase to 19 million by 2050 (five percent of the US population).

As the elderly population continues to grow, diseases such as dementia, have a devastating impact on the older population and society. Currently 4 million Americans suffer from AD. This number is expected to increase to 14 million by 2050 (Bonner and Peskind, 2002). The growing number of

patients with AD has both public health and economic consequences. Alzheimer's disease contributes to greater than 100,000 deaths each year in the United States (Chen et al, 2000). Additionally, the annual cost of AD to society is approximately \$100 billion (Alzheimer's Association, 2002).

As the United States witnesses an explosion of the elderly population, there will be a marked increase in the diversity of this population (See Table 2). This growth is of concern since dementing disorders have been found to be high or higher in African Americans and Hispanics than Caucasians (Tang et al, 1998). As the non-Hispanic Caucasian population 65 and older, decreases from 84% in 2000 to 64% in 2050, there will be an increase in the ethnic minority population. Further, the fastest growing will be the Hispanic older population, with a projection of 2 million in 2000 to over 13 million by 2050.

**Table 2. Projected Distribution of the Population Aged 65 and Older, 2000 and 2050 (United States Bureau of the Census, 2001)**

<b>Ethnicity</b>	<b>2000</b>	<b>2050</b>
Non- Hispanic White	84%	64%
Hispanic	6%	16%
Non-Hispanic Black	8%	12%
Non-Hispanic Asian and Pacific Islander	%	7%
Non-Hispanic American Indian and Alaskan Native	0.4%	0.6%

Yet, there is little scientific literature on dementia as it relates to ethnic minority elders. This is mostly due to the under-representation of minority elders in research (Morse et al., 1995; Lovato et al., 1997; Mouton et al., 1997; Stoy et al., 1995; Coleman et al., 1997; Moody et al., 1995; Areal and Gallagher-Thompson, 1996; Sinclair et al., 2000; Hall, 1999). For example, as part of the Genetics, Response and Cognitive Enhancers (GRACE) Conference, the data sets from Alzheimer's trials, including the National Institute on Aging (NIA)'s Alzheimer's Disease Cooperative Study (ADCS), and Phase II and III clinical trials for acetylcholinesterase inhibitors (galantamine, sabeluzole, and rivastigmine), were examined. Minorities represented only 3.6% (420) of the combined number of subjects enrolled in all studies (N=11,537) (GRACE, 2000).

### **PREVALENCE AND PRESENTATION OF BPSD**

Numerous studies have evaluated the prevalence and nature of BPSD (Jeste and Finkel, 2000; Chen et al, 2000; Chung and Cummings, 2000; Paulsen et al, 1999; Cohen et al, 1996; Mega et al, 1996; Levy et al 1996; Cohen, et al 1993; Wragg and Jeste, 1989; Cooper, 1991; Deutsch, 1991). The reported prevalence of BPSD varies in AD literature as a result of a number of factors, including methodological variability, differences of inclusion and exclusion criteria and selection bias in the referral population (Chung and Cummings, 2000). Further, much of the literature is limited by methodological concerns, including the inclusion of heterogeneous groups of dementia patients and small sample sizes. Studies that have evaluated the prevalence and presentation of BPSD across racial and ethnic groups in the United States have not been methodologically rigorous.

Nevertheless, summaries of three articles evaluating the BPSD across racial and ethnic groups in the United States are presented here, to highlight potential racial and ethnic differences and illustrate specific methodological issues.

**Cohen C, Magai C. *Racial differences in neuropsychiatric symptoms among dementia outpatients.* Am J Geriatr Psychiatry 1999; 7: 57-63.**

Description: 240 outpatients (78% women) with either Alzheimer's disease or multi-infarct dementia were evaluated to examine whether race has independent effects on the prevalence and levels of neuropsychiatric symptoms of dementia). The patients were evaluated at the Brooklyn Alzheimer's Disease Assistance Center of the State University of New York from 1992-1995. Sixty-eight percent of the cohort were African American (n =164) and 32% were Caucasian (n=76). Of the African American cohort, 63% were born in the United States and 37% were African Caribbean. Patients were diagnosed with dementia according to DMS-III-R criteria resulting in a cohort with 70% AD; 17% with multi-infarct dementia; and 14% exhibiting features of AD and some mixed features. The authors specifically investigated psychoses, agitation, and depression in this group utilizing BEHAVE-AD.

Specific findings:

- Depressive affect was noted to be significantly higher in Caucasians ( $p < 0.05$ ) as compared to African Americans. These findings are consistent with data showing fewer depressive symptoms among black nursing home residents (Walker et al, 1995) and among black outpatients with dementia (Fabrega et al, 1988).
- Psychoses and activity disturbance were noted to be significantly higher in African Americans ( $p < 0.01$  and  $p < 0.05$ , respectively), as compared to Caucasians. These findings are consistent with other published literature (Cohen and Carlin, 1993; Cohen et al., 1996).
- After multivariate analysis, depressive affect and psychoses remained significant.
- No significant differences in symptoms were noted between United States-born African Americans and African Caribbeans.
- Differences between African Americans and Caucasians most likely due to racial differences in types of symptoms precipitating evaluation. The lack of significant differences between United States-born African Americans and African Caribbeans suggest that differences between African Americans and Caucasians may have biological or genetic etiology.

Limitations:

- The study population was not a random sample. The study population was selected from patients brought to the center for evaluation. The racial differences may be then, reflections of symptom perception and caregiver tolerance. Additionally, the authors suggest that African Caribbeans' presentation to the evaluation center may be due to acculturation. The authors note the possibility of different levels of symptomatology among African Caribbeans with dementia who have not received evaluation and treatment in the community setting, in comparison to African Caribbeans with dementia seeking evaluation and treatment.
- The study involved a small sample size (n = 240).
- The study population contained a heterogeneous group of dementia patients. The authors report, however, the correlations between the dementia types and symptoms ranged from 0.06 to 0.09. Regression analysis revealed non-significant  $t$  values.

**Chen J, Borson S, Scanlan J. *Stage-specific prevalence of behavioral symptoms in Alzheimer's disease in a multi-ethnic community sample.* Am J Geriatr Psychiatry 2000; 8(2):123-133.**

Description: At the University of Washington Alzheimer's Disease Research Center (ADRC), 125 outpatients with probable and possible AD were evaluated for the purpose of investigating their behavioral symptoms and their association to AD severity. The study population included 38 African-Americans, 63 Asian Americans/Pacific Islanders, 17 Hispanics and 7 Native African-Americans/Alaskan Natives. A large number of the study population was non-English speaking immigrants, and 75% were women. Patients were diagnosed with dementia using the DSM-IV criteria for DAT and NINCDS/ADRDA. Based on these criteria, 108 were diagnosed with probable AD, and 17 were diagnosed with possible AD. Behavioral symptoms were evaluated utilizing BEHAVE-AD.

Specific Findings:

- No significant differences were found in the severity of dementia among the ethnic groups.
- Hispanics were noted to have a significantly higher total behavioral symptom score compared to Blacks.
- Blacks reported a lower overall prevalence of behavioral symptoms compared to the other ethnic groups.
- Blacks reported significantly reduced depressive, anxiety, and sleep symptoms compared to Asians and Hispanics.

Limitations:

- The BEHAVE-AD scale may not have been appropriate for assessing symptoms in this multi-ethnic population as it has not been validated across all cultures. There are additional concerns about whether caregiver reports via BEHAVE-AD are a representation of under- or over-reporting by caregivers versus actual exhibition of symptoms by patients
- Subjects were identified via convenience sampling.
- Ethnic groups were represented by small sample sizes. Further, no investigation for differences within the different ethnic groups was made.

**Mintzer J, Nietert P, Costa K, Waid L. *Agitation in Demented Patients in the United States. International Psychogeriatrics, 1996; 8 (Suppl 3) 487-490.***

Description: Two studies to assess the presence and compare the characteristics of agitation were conducted in two different settings. The purpose of each was to evaluate the presence and characteristics of agitation in African American and Caucasian patients with dementia, living in either a nursing home or at home with a caregiver. Dementia was defined using DSM-III criteria. The Cohen-Mansfield definition of agitation (i.e., inappropriate behavior unrelated to unmet needs or confusion per se) was used. Agitation was categorized according to the following three factors identified on the Cohen-Mansfield Agitation Inventory (CMAI):

- Aggressive behavior (e.g., hitting, kicking, pushing, scratching, tearing things, cursing or verbal aggression, grabbing, biting, spitting)
- Physically non-aggressive behavior (e.g., pacing, inappropriate dressing or undressing, repetitious sentences or questions, trying to get to a different place, handling things inappropriately, general restlessness, repetitious mannerisms)
- Verbally agitated behavior (e.g., complaining, constant requests for attention, negativism, repetitious sentences or questions, screaming).

Study I: Nursing Home

An evaluation of 104 agitated patients with dementia was conducted. The skilled nursing home patients were recruited from 12 centers as part of a multi-center clinical trial. There were 93 Caucasians and 11 African Americans. Of the Caucasian group, 62% were women. The African American group, however, had 73% men.

Specific Findings:

- African-Americans had a significantly higher prevalence of aggressive behavior than Caucasians.
- Caucasians had a slightly higher prevalence of physically non-aggressive behaviors and verbally agitated behaviors compared with African-Americans, but the differences were not statistically significant.

Study II: Home with a Caregiver

A small group of 104 agitated patients with dementia were evaluated after being admitted to a geriatric psychiatry unit. There were 86 Caucasians and 24 African Americans. The study population included 40 men.

Specific Findings:

- In the home setting, Caucasians exhibited significantly more verbally agitated behaviors than African-Americans ( $p < 0.005$ ) although the overall level of agitation was not significantly different between the two ethnic groups.
- No significant differences in the prevalence of aggressive and physically non-aggressive behaviors were found between African-Americans and Caucasians.

Although African American patients had a higher prevalence of aggressive agitated behavior in nursing homes than Caucasians, these differences were not elucidated in the community-based sample. Overall, the authors conclude that differences in agitated behavior appear to depend more on the setting than the patient's race.

Limitations of studies:

- The authors did not control for differences between AD and multi-infarct dementia. This may have particularly had an effect on Study I since a larger percentage of vascular dementia among African American patients may have resulted in increased aggressive behaviors.
- Severity of dementia was not controlled.
- Studies involved small sample sizes.

## **ASSESSMENT OF DEMENTIA AND BPSD**

The actual assessment of dementia must be made before BPSD can be appropriately assessed. As stated previously, a major goal is to develop culturally accurate measures that can be utilized in all ethnic populations (GRACE, 2000). Clinicians and researchers must be aware that in the United States, ethnic groups differ from each other by language, communication, quality of education—all of which can contribute to misdiagnosis (Manly, 2002; Espino and Lewis, 1998).

A number of studies in the United States have reported a significantly higher risk of developing Alzheimer's disease in African-Americans and Hispanics as compared to Caucasians, even after correcting for years of education (GRACE, 2000). Do these reports represent an increased prevalence of dementia or, inaccurate assessments based on educational and/or literacy level? Manly et al, 2000, caution that the quality of education differs between countries, but also within each country (GRACE, 2000; Manly et al, 2000; Manly et al, 1999.) As such, matching ethnic groups on the basis of their years of education may be based on an inappropriate assumption that the quality of education is comparable. (Manly, 2000)

Another factor regarding the assessment of dementia is the caregiver-patient relationship since many scales and assessments require information from the caregiver (Sano, 2000; GRACE, 2000). Cultural differences have been noted in caregivers. For example, caregivers tend to be spouses for Caucasian patients, while caregivers tend to be children or siblings for African-American and Hispanic patients. In the future, the effect of caregiver relationship on outcome measures will need to be explored.

### **Approaches to Management**

There have been few double-blind, placebo-controlled studies evaluating treatments of BPSD. For general considerations about specific treatments, dosing, and side effects, see Module 6. For general considerations regarding non-pharmacological treatments of BPSD, see Module 5). Further, methodologically rigorous data is lacking in the evaluation of cultural differences in the management of BPSD in the United States. Recent information has shown that racial and ethnic differences could be responsible for differences in drug metabolism, side effect profile, and treatment (Tang et al, 1998; Chang et al, 1991; Jann et al, 1989). Scientifically sound data is needed to evaluate the treatment of BPSD across racial and ethnic groups in the United States.

BPSD are common precipitants of nursing home admissions in the United States and a source of caregiver stress (Velez and Pega, 2001; Madhusoodanan, 2001; Chung and Cummings, 2000). The percentage of persons 65 years and older residing in United States nursing homes has decreased from 5.1 percent in 1990 to 4.5 percent in 2000 (US Census Bureau, 2000). Data suggest that minorities utilize nursing home care services less than non-minorities (Espino and Lewis, 1998; Walker et al, 1995; Valle, 1993). For example, data suggest that African American elderly utilize nursing homes at 50-75% the rate of Caucasians (Walker et al, 1995)

### **BPSD in Turkey**

Studying BPSD across cultures allows the identification of similarities and differences that may be useful to determine the best approaches to management of these symptoms. Although the behavioral and psychological symptoms comprise one of the major symptomatology domains of age-associated dementia, BPSD are not yet regarded as a major health issue in Turkey or other developing countries. However, according to the latest Turkish census, the total population of Turkey is 65, 666,700. The current life expectancy is 71 years (male = 69 years; female = 74 years). Those 60 years old and older represented 7% of the total population. BPSD will no doubt become a management issue in the near future. Turkish family practitioners, residents in psychiatry and neurology, and even psychiatrists and neurologists do not, in general, have sufficient experience to evaluate and treat BPSD (Eker et al, 2000).

### **Assessment and Frequency of BPSD**

The Istanbul University, Cerrahpasa Medical School, Department of Geriatric Psychiatry is the only inpatient clinic in Istanbul. There is a memory outpatient clinic associated with this department. Since 1993 patients with AD have been referred to the outpatient clinic. One of the research objectives is to study the outpatient clinic population in order to examine behavioral and psychological symptoms in Turkish Alzheimer's patients.

In a recent study on BPSD, presented at the 2002 World Psychiatric Association Congress in Yokohama, Japan, 190 patients with probable AD (DSM-IV, 1994), admitted (consecutively to the memory outpatient clinic, were assessed. The Turkish version of the MMSE for educated and uneducated patients was used (Gungen, Ertan, Eker, et al, 1999).

Their dementia was staged using the Global Deterioration Scale (GDS) (Reisberg et al, 1982). Specific behavioral symptoms were systematically assessed by using the Behavioral Pathology in Alzheimer's Disease Rating Scale (BEHAVE-AD) (Reisberg et al, 1987).

The present study demonstrated that BPSD were found very frequently, in 91.5 % of AD cases. The BPSD occurred most frequently in stage 6 (severe dementia). The most frequently occurring symptoms in Turkish AD patients were purposeless activity, the delusion that “people are stealing things,” wandering, tearfulness and fear of being left alone.

In Turkey, patients in later stages of Alzheimer’s disease, i.e., GDS stages 5 and 6 are seen by neurologists and psychiatrists in outpatient clinics. Specialists interested in BPSD take the history and conduct physical, psychiatric, and neurological examinations. The DSM-IV and NINCDS-ADRDA are widely used. The Turkish version of the MMSE is the most widely used brief cognitive screening test; only a minority of Turkish psychiatrists and neurologists use the GDS and BEHAVE-AD.

Turkish family members are more likely to report behavioral and psychological symptoms rather than memory problems in their parents or relatives. Caregivers may under-report BPSD because they fear their relatives are mentally ill. On the other hand, their desire is not to relinquish their caregiver role or religious values. The Turkish culture has traditionally emphasized paternal authority and family loyalty, and children are typically expected to care for their parents who have dementia. Relatives who are caregivers of AD patients with BPSD do not want to place their charges in nursing homes. On the other hand, Turkey does not provide good quality services for AD patients (Eker, 1995). Patients with BPSD are usually placed in general psychiatry departments, and are treated by general psychiatrists who often lack sufficient knowledge of mental disorders in old age. There is a drastic shortage of centers that can provide care for patients with dementia and BPSD. In Turkey, patients with dementia are mostly cared for their by their spouses or the eldest daughter in their homes. They are only admitted to a specialist unit when BPSD are severe.

### **Approaches to Management**

- Although there are no guidelines for prescribing neuroleptics in patients with dementia, they are and have been the drugs of choice for treating BPSD. Historically, haloperidol and trithioperazine have been used. Recently, atypical antipsychotics (risperidone olanzapine and quetiapine) have been used in controlling psychosis and aggressive behavior.
- SSRI’s are used to treat the depression associated with AD.
- Mood stabilizers are used in situations where first line therapy has proven unsatisfactory for treatment of BPSD.
- Although staffs in institutions are not well-educated in the use of behavioral (non-pharmacological) interventions in the treatment of BPSD, the value of these interventions is being recognized by some nursing home medical staff.
- Taking care of the elderly having AD at home project has come true in the large cities. Some educated voluntary groups are engaged in looking after these patients.
- One of the main topics of recent meetings of Turkish Psychogeriatric and National Geriatric Societies is BPSD. At these meetings, general practitioners, neurologists, psychiatrists and caregivers of persons with dementia are educated on the topic.

### **BPSD in India**

#### **Historical background**

Historically, India has been a rural, agricultural society. A joint family system has traditionally prevailed with several generations, and often multiple families from each generation, living together. In a system with many people living together, most of whom were able-bodied and working, the vulnerable were easily cared for, and this significantly lessened the burden of care. Over the last many years things have changed and the joint family system is under stress. The emerging pattern is:

- multiple families of the same generation no longer living together
- the substantial burden of caring for frail or sick elderly falling on only one or two caregivers
- substantial, prolonged stress on individual caregivers
- animosity against both the elderly and other family members who do not share in the care giving.

Cognitive decline with age is well recognized in ancient Indian culture. Around 800 BC, a term ‘Smriti Bhransh’ was described in the Ayurvedic literature implying ‘loss of memory’ and a treatment for this condition was described. A term currently used in the Indian language to describe cognitive impairment translates literally as ‘turned 60’. This term is used to describe patients who begin to exhibit signs and symptoms of cognitive decline, whatever their actual age. Since this phrase has been part of the language for centuries, it indicates that cognitive impairment was considered to be a part of aging, not a disease. In some parts of the southern state of Kerala, a term “Chinnan” is used to denote dementia-like condition (Shaji et al, 2002). The symptoms, considered to be indicative of affliction with “Chinnan”, include inappropriate behavior, childish behavior, and incontinence apart from failing memory. Again, this is considered part of the aging process rather than a disease during old age.

### **BPSD and Burden of Care**

The 10/66 dementia research group studied the care arrangements for dementia patients. The unpublished data includes information on 179 patients from India. Most caregivers were women, living with the person with dementia in extended family households. More than half of households included a child. However, despite the traditional apparatus of family care, levels of caregiver strain were at least as high as in the developed world. Many had cut back on work hours to be caregivers but still faced the additional expense of paid caregivers and health services. Findings of the study suggest that older people in India, like other developing countries, are indivisible from their younger family members. The high levels of family strain identified in this study feed into the cycle of disadvantage, and should thus be a concern for policymakers.

### **Nature and Prevalence of BPSD**

Based on early reports from centers engaged in dementia research, the prevalence of BPSD in India may not be very different from that found in other parts of the world. The Thrissur Center of the 10/66 dementia research group assessed BPSD in a sample of 17 patients meeting the DSM-IV diagnosis of Alzheimer’s disease presented at the Annual Conference of ARDSI at New Delhi in 2000. Data from this study is compared with the data from the two other reports from the 10/66 researchers presented by Dr Mathew Verghese from Bangalore and Dr. S. Shaji from Cochin at the Annual Conference of ARDSI at Goa in 2002. See Table 3 for details.

All three studies utilized the BEHAVE-AD to make their prospective assessments.

**Table 3. BPSD – PRELIMINARY REPORTS FROM INDIA**

<b>Behave – AD Items</b>	<b>Thrissur Community Sample with AD (N =17)</b>	<b>Bangalore Outpatients with Dementia (N=31)</b>	<b>Cochin Outpatients with AD (N=40)</b>
One or more BPSD	88.2%	83.9%	-----
Paranoid and delusional ideation	53%	35.5%	65%

Hallucinations	29%	12.9%	25%
Activity disturbances	88.2%	58.1%	73%
Aggressiveness	76.5%	64.5%	78%
Diurnal rhythm disturbances	58.8%	51.6%	60%
Affective disturbances	29.4 %	32.3%	25%
Anxiety and phobias	23.5%	6.5%	36%

High prevalence of BPSD in these samples suggests that these symptoms are common in India too. These symptoms cause severe stress on the co-resident caregivers, who receive no support or guidance from the existing health care delivery system. In a qualitative study (Shaji et al, 2003) caregivers described BPSD and incontinence as the most distressing and difficult to manage symptoms.

Aggression, agitation and wandering are the most commonly seen BPSD. The prevalence of these symptoms is comparable to the frequency reported for other countries (Homma et al, 2000; Mangone et al, 2000) and from the western developed countries. However, more information is needed from larger representative community samples of patients from other parts of India before making useful comparisons about individuals' symptoms. The available information comes from preliminary studies conducted in South India.

### **Approaches to Management**

The prevailing low level of public awareness of dementia in India has many implications. It reduces the chances of correct identification and management of BPSD in the community. BPSD are frequently misinterpreted by the relatives as deliberate misbehavior by the patient. BPSD are sometimes misinterpreted by others as evidence of poor quality of care provided by the family. Allegations of this kind add to the misery of the caregiver and frequently result in interpersonal problems.

Since elderly patients with AD (or other types of dementia) are not often brought to a physician's attention, many BPSD go untreated. Even for those BPSD for which adequate treatments are available, it is hard to find a physician skilled in their diagnosis and treatment. There are no support groups to help family members and consequently both the patient and their families can suffer.

Given the prospect of the increase in the number of old people affected by dementia in the developing world, we need to develop strategies that will assist families caring for persons with dementia at home. The development of simple, culturally-acceptable, non-pharmacological interventions for the management of BPSD in the community would be an important step in this direction. Once the feasibility and cost effectiveness of such interventions are established, they could provide an important ingredient of community based dementia care services in developing countries. Informing and educating the family members and giving them continued support and guidance in managing BPSD at home has the potential for wide application in developing countries.

The Indian network of the multi-center 10/66 Dementia Research Group is developing community-based interventions to be administered by multi-purpose health workers (MPHWs). The health and social welfare systems of several developing countries utilize the services of community-based health workers. Workers who have achieved a basic standard of education receive additional training in simple health care programs. They are generally assigned to a catchment area. They get to know all of the families in their local area, and visit their homes principally to monitor maternal and child health and development. MPHWS are in many developing regions the only generally available outreach arm of health care services as primary care teams often do not venture outside of their clinics. In principle, MPHWS could receive appropriate training and extend their role

to include basic family and community interventions for people with dementia. The training package for MPHWs would necessarily include at least three components: 1) general information about dementia; 2) training regarding detection of dementia in the community; and, 3) training in the implementation of various interventions. Management of BPSD, especially non-pharmacological approaches, would be given due emphasis in this intervention. Since many caregivers have low literacy levels, special educational aids and teaching materials would be provided. Such educational material would be developed locally and adapted to the cultural and linguistic differences.

There are changes occurring in India too. The Alzheimer's and Related Disorders Society of India (ARDSI) with many chapters all over India has, to some extent, succeeded in increasing the level of awareness about dementia. The plight of the families who look after relatives with dementia at home is being recognized and discussed. Specialized dementia care services, which focus on the management of BPSD, are likely to come up in many general hospitals which are usually located in the urban areas. This is primarily because of increasing demand for such services from the educated sections of the society. In addition, the availability of many drugs useful in the management of BPSD has brightened the prospect of better management of these symptoms. The prospect of networking centers that provide specialized dementia care is also being discussed. It is anticipated that abundant information about the management of BPSD will be available in the next few years, once specialized dementia care services are established in many general hospitals in India.

### **BPSD in Argentina**

Population aging is a process that is especially accelerated in some parts of the world. Latin America has to confront population "graying" in the context of an emerging economy. Countries such as Chile, Argentina, Uruguay and Mexico face the aging of their populations. In other countries, including Haiti, Bolivia and Guatemala, population aging will be delayed by continued high birth rates. Even so, by 2002, the elderly population will be increasing more rapidly than other populations in the world (Mangone et al, 2000).

Argentina is populated by a mixture of different ethnic cultures; however, unlike other Latin American countries, most Argentinean people are of central and west European descent. The second largest ethnic group is the mestizos, a fusion of European immigrants and native aborigines, followed by the native aborigines who live in special reserves. The North and West are populated by a greater proportion of natives and mestizos living in rural areas, the center, and the southeast, by European descendants.

Argentina has one of the largest elderly populations in Latin America due to a life expectancy of 73.9 years (World Bank, 2002). In Buenos Aires, the elderly constitute 20.6% of the population. According to the 2001 Argentinean National Census, 4.7 million of the total population of 37.5 million persons is older than 60 years. The urban population was 88.3% of the total. The adult illiteracy rate was 3.1% in the population over 15 years old and 8.6% over 65. However, a high percentage of persons older than 60 years are functionally illiterate, with fewer than four years of schooling. The low literacy rate of this group makes it difficult to assess the cognitive abilities of these people. Clinicians must adapt assessment instruments not only to the patients' language and culture, but also to their educational level.

Argentineans have traditionally been involved in caring for the elderly. In 1971, the National Government created the Institute for the Elderly (ISSPJP) to take care of the social and medical needs of retired people. The Institute provides care for approximately 70% of individuals over 60 years old and 90% of those over 75 years old.

A pilot study conducted by the 10/66 dementia research group was developed in Buenos Aires in 2001. The economic cost of AD in Argentina (Allegri et al, 2002) ranged from \$6,739 in patients with mild AD, to \$9,541 in severe AD patients. The total annual estimated cost was \$4,000,000,000 each year. With projected increases in the number of persons at risk for developing AD in Latin America, the economic impact of the disease in the future will be highly significant. The direct costs of the disease increased with cognitive deterioration for the community-dwelling group-- outpatients \$3,189; and for institutionalized patients \$11,270.

Most senior citizens live at home with their family; approximately 15% are institutionalized in nursing homes. This arrangement may result partly from the tradition of extended families, but also evolves from the high cost of nursing home care.

Of the 20,000 nursing home beds in Buenos Aires and the greater Buenos Aires area, only 5% are specialized neurology or psychiatry beds. From 42% - 50% of patients are in unspecialized nursing homes, while 64% of those in specialized nursing homes have dementia (Taragano et al., 1995). Thus, 13,500 of the available nursing home beds in Buenos Aires and its greater area are for patients with dementia.

The economic problems in Argentina combined with the low incomes of certain social groups further complicate the assessment and treatment of persons with dementia.

### Frequency of BPSD

In Argentina, the Neuropsychiatric Inventory and the Behavioral Pathology in Alzheimer's Disease Rating Scale (BEHAVE-AD) are the most common tools used to assess BPSD. A study by Pollero et al, in press, has looked at the frequency of BPSD (87.5%) in 72 patients with AD using the Neuropsychiatric Inventory NPI-Q (Kaufert et al, 2000) (see Table 1). The most frequent symptoms were apathy, irritability, depression and anxiety.

**Table 4: BPSD in 72 patients with AD (NPI-Q)**

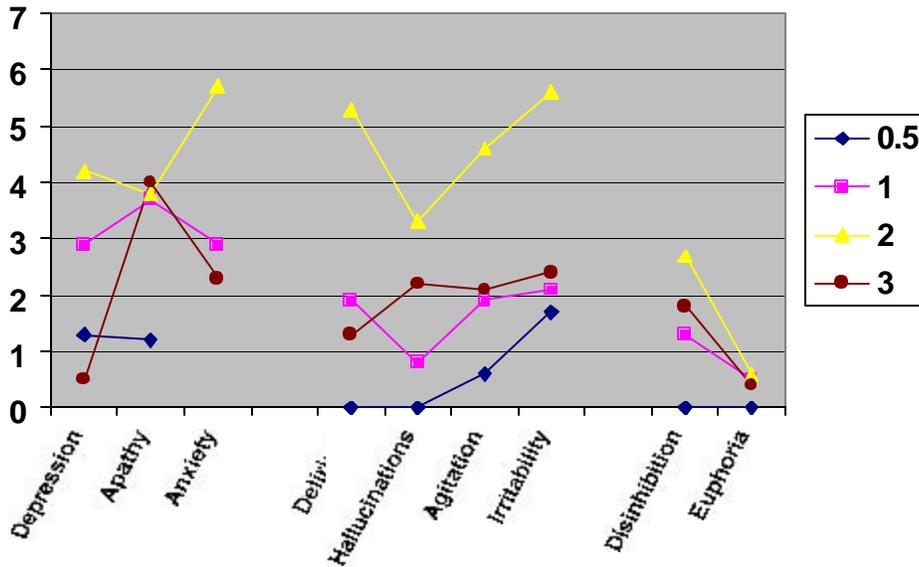
<b>BPSD</b>	<b>M ± SD</b>	<b>n</b>	<b>% Patients</b>
Delusions	2.11 (+ 3.7)	22	30.5
Hallucinations	1.8 (+ 3.4)	22	30.5
Agitation	2.3 (+ 4)	24	33.3
Depression	2.2 (+ 3.3)	33	45.8
Anxiety	3.1 (+ 4)	36	50.0
Euphoria	0.4 (+ 1.9)	6	8.3
Apathy	3.7 (+ 4.7)	40	55.5
Disinhibition	1.6 (+ 3.4)	17	23.6
Irritability	2.9 (+ 3.8)	40	55.5
Motor Behaviors	1.5 (+ 3.5)	15	20.8
Sleep Disorders	2.1 (+ 4)	21	29.1
Appetite	1.3 (+ 3.1)	15	20.8

The NPI range was 0 -12 (Frequency x Severity)

The sample was divided by the Clinical Dementia Rating (CDR, Hughes et al, 1982) from 0.5 to 3 (see Figure 1). Mood symptoms were predominant in very mild and mild dementia, while psychotic

symptoms were predominant in moderate dementia. Apathy was the symptom most prevalent in all levels of dementia.

**Figure 1:**  
Neuropsychiatric symptoms by level of dementia (CDR)



The NPI range was 0-12 (Frequency x Severity)  
(Clustered by Symptoms - Depression, Psychosis, or Frontal)

### BPSD and Caregiver Burden

The relationship between the caregivers' feelings of burden and the cognitive, behavioral, and functional impairment of patients with dementia has been investigated in an Argentinean study of 85 patients with probable AD (Mangone et al., 1993). BPSD and caregiver burden were assessed using the Functional Dementia Scale in the Blessed Dementia Scale and an adapted version of the Zarit Burden Interview, respectively. The study showed that caregiver reports of patients exhibiting BPSD were the best predictors of burden on the part of the caregiver. Aggressiveness, pacing, moaning or shouting were among the items on the Functional Dementia Scale that were identified as independent predictors of caregiver burden. Interestingly, the study found that caregiver burden may foster a growing intolerance of patients' functional limitations, leading to frustration on the part of the patient which, coupled with impulsivity, impaired judgment and low self-esteem, can lead to agitated behavior or catastrophic reactions.

Caregiver characteristics predictive of caregiver burden were age and level of education. Younger, more educated caregivers experienced uncertainty and inability to cope. The older the caregiver the greater the feeling of obligation to care for the patient; thus, older caregivers were more likely to neglect their own health and reject respite care offered to them. Direct assessment of patients indicated that their level of functional performance (primarily in shopping, feeding, dressing and ambulation) was often underestimated by caregivers.

## Approaches to Management

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- In Argentina, there are subtle differences in the frequency of BPSD for which caregivers seek immediate treatment, depending on the caregivers' cultural background.
- 

Treatment depends on psychosocial and demographic factors.

1. Caregivers living in Buenos Aires, the surrounding area, or in principal cities, such as Cordoba, Rosario, and Mendoza, are more likely to request treatment for the following BPSD:
  - a. Agitated behavior (e.g., compulsive behavior, irritability, catastrophic reactions)
  - b. Pacing or wandering – this form of motor agitation is one of the most frequent predictors of burden among caregivers living in large cities, but not of those in the provinces, where most patients live in a house with room enough to pace and without the danger of becoming lost.
  - c. Sexual problems (e.g., sexual disinhibition, sexual misdemeanors) – these symptoms are less problematic in the provinces because, culturally, caregivers are too embarrassed to confess that their relative has sexual problems.
  - d. Apathy and depression – surprisingly, apathy was more frequently reported than depression as a cause of caregiver burden
  - e. Delusions – ‘my house is not my home’ and misidentification of the caregiver, particularly if the caregiver is a spouse, are the most troublesome
  - f. Sleep disorders (e.g., insomnia, rapid-eye-movement sleep behavior disorder)
2. Illiterate caregivers, most of whom are mestizos or natives, living in smaller cities and rural areas, are more tolerant of BPSD and seek treatment only when behavioral problems become overwhelming. These caregivers are convinced they are obliged to care for their relative and are likely to keep others from knowing the difficulty of their care-giving situation. They also rely on prayer and their faith to handle problems related to caregiver burden. The symptoms for which these caregivers most frequently request treatment are:
  - a. Aggressiveness
  - b. Sleep disorders
  - c. Delusions or hallucinations.

General practitioners consider cognitive symptoms and BPSD to be part of the normal aging process and they do not perform a meticulous diagnosis. Specialists (neurologists, psychiatrists and geriatricians), are unevenly distributed in the country, most of them located within large towns. There is a shortage of specialists in small towns and in the rural areas. The facilities needed for accurate diagnosis are scarce, except within Buenos Aires and a few other large provincial cities. Few young physicians are properly trained in dementia diagnosis and treatment during their medical residency, and there are few specialists trained in dementia.

The pharmacological treatment approaches are similar to those in the USA... There are support groups (Association against Alzheimer's disease and Related Disorders of Argentina – ALMA) to help family members, but many are reluctant to use them. Clearly, more public education about dementia for lay people is needed throughout Argentina (Mangone et al 2000).

## BPSD in Taiwan

Alzheimer's disease is the most common cause of dementia in Taiwan and many patients with AD manifest BPSD. Until recently, most research has focused on the neurobiological aspects of dementia and cognitive impairment, while BPSD have been relatively neglected.

Recent studies show that Taiwanese AD patients exhibit many of the BPSD described in studies using European or USA populations:

**Table 5. BPSD in Taiwan (Liu, 1999; 1995; Tsai, 1997; Hwang, 2000; 1997; 1996):**

BPSD	Study in Psychiatry Tsai, 1997; Hwang, 2000; 1997; 1996	Study in Neurology (Liu, 1999)
Depression		
Depressive symptoms		22.0%
Major depression		5.0%
Minor depression		11.3%
Anxiety		35.3%
Delusions	62.9% (Hwang, 1996)	27.2%
Delusion of theft	55.6% (Hwang, 1996)	27.2%
Persecutory delusion	24.1% (Hwang, 1996)	28.0%
Delusion of infidelity	16.7% (Hwang, 1996) 15.8 % (Tsai, 1997)	3.4
Delusion of abandonment	9.3(Hwang, 1996)	2.2%
Misidentification of someone in the house	22% (Liu, 1995;Hwang,1996)	2.2%
Misidentification of people	111.1% (Liu, 1995;Hwang, 1996)	3.4%
Misidentification of TV	9.3% (Liu, 1995)	
Misidentification of mirror image	7.4% (Liu, 1995)	
Misidentification of the house is not patient's home	16.7 (Liu, 1995)	16.5%
Hallucination	25.9% (Hwang, 1996)	
Visual Hallucination	14.8% (Hwang, 1996)	19.5%
Auditory Hallucination	16.7% (Hwang, 1996)	11.6%
Tactile Hallucination		0.7%
Olfactory Hallucination		0.7%
Hyperphagia	30.8% (Tsai, 1996) 36.0% (Hwang, 1996)	
Pica	7.7% (Tsai,1996)	
Verbal aggression		21.4%
Violence	57.4% (Tsai,1996) 54.7% (Hwang, 1996)	10.3%
Hoarding	22.6% (Tsai,1998)	
Getting lost	45.3% (Hwang, 1997)	25.8%
Repetitive phenomena	62.7% (Hwang, 1997) 56.0% (Hwang, 1997)	26.4%
Sleep disturbance	61.3% (Hwang, 1997)	23.4%
Inappropriate sexual behavior	10.7% (Hwang, 1997)	

A number of these symptoms (wandering, hyperphagia and sleep disturbance) were associated with the severity of cognitive impairment (Hwang et al., 1997). Studies in Hong Kong also revealed that BPSD are highly prevalent. Some symptoms are stage specific, most behavioral problems peak in the moderate stage and attenuate as dementia progresses.

## BPSD in Africa and the Caribbean

### Prevalence and presentation

Differences in the prevalence and levels of tolerance of BPSD in a Nigerian community (the Yoruba people living in Ibadan, Nigeria), a Jamaican community (in Kingston, Jamaica) and an African-American community (living in Indianapolis, Indiana, USA) have been described (Hendrie et al., 1996). Ibadan is a major Nigerian city of more than 1 million people; however, despite its urban setting, the Yoruba community functions much like a village. The Jamaican population studied lives in a poor suburb of Kingston, and the African-American population in a moderate-size city of approximately 1 million people.

**Table 6. Prevalence (%) of selected BPSD and functional deficits in the USA, Jamaica and Nigeria. Reprinted with permission from Hendrie et al., 1996.**

<b>BPSD and Functional Deficits</b>	<b>Indianapolis Indiana, USA (n=50)</b>	<b>Kingston Jamaica (n=18)</b>	<b>Ibadan Nigeria (n=28)</b>
<b>Personal care</b>			
Feeds self	57	64	86
Dresses self	42	28	75
Personal hygiene	42	28	75
Lost in community	22	50	15
<b>Changes in personality</b>			
Any change*	64	29	37
Stubborn or obstinate	72	50	26
Irritable or angry	52	33	19
Inappropriate behavior in public	17	19	26
<b>Psychiatric symptoms</b>			
Depression	14	6	4
Delusions	21	18	4
Hallucinations	4	22	4

\*Reflects the clinician's opinion as to whether the change significantly affected caregiving. The percentage in this category may be lower than that for the other subcategories.

Data regarding the prevalence of BPSD in the different communities were gathered from caregiver reports. The findings are presented in Table 4. It should be borne in mind that these data are not corrected for age and severity of dementia among populations, and so direct comparison between groups is difficult. Dementia was most severe in the Jamaican sample (previously identified dementia patients attending a medical clinic) and least severe in the Nigerian sample (patients with dementia identified as part of a community study).

The comparison showed that:

- African-American and Jamaican patients were less likely than Nigerians to complete tasks related to personal care (functional ability) and more likely to become lost in the community.
- Caregivers of African-American patients were more likely to report changes in personality – whether this reflects a real difference in the number of patients with personality changes or a difference in the level of tolerance to such symptoms is not clear.
- Nigerian caregivers were clearly more concerned than their counterparts in the USA and Jamaica by their demented relatives becoming involved in situations they regarded as embarrassing.

- Neither Nigerian nor Jamaican caregivers reported depression associated with dementia as a significant symptom.

### Approaches to Management

In the study reported above (Hendrie et al, 1996), data on most troublesome symptoms reported by caregivers and most likely treatments were obtained from the study investigators who were also involved in providing healthcare to these elderly populations. Table 5 summarizes these findings.

**Table 7. Treatment of BPSD in Jamaica and Nigeria. Adapted with permission from Hendrie et al, 1996**

	<b>Kingston Jamaica</b>	<b>Ibadan, Nigeria</b>
Recognized	Yes	Yes
Treatment available	Yes	Partially
Treatment sought	Yes	Seldom
More troublesome symptoms:	Agitation	Agitation
	Wandering	Violence
	Violence	Delusions
	Sleeplessness	Hallucinations
Type of treatment:	Pharmacotherapy	Little direct
	and milieu therapy	treatment

Treatment depends largely on psychosocial and demographic factors, as has been noted earlier. In both Jamaican and Nigerian societies, the elderly are held in high regard and considered as repositories of knowledge; thus a considerable degree of tolerance towards BPSD is seen. Nigerians have a saying that in old age, people become children again, despite their wisdom.

Early cognitive symptoms and BPSD are often misinterpreted by caregivers. In Jamaica, decreased cognitive function is often misunderstood by relatives and reported as 'difficult' behavior. Repeated question asking is seen as 'attention-seeking' – a finding reported in a number of studies of caregiver perceptions in European and USA populations. In Nigeria, caregivers often do not report symptoms such as hallucinations and delusions in their demented relative for fear of a diagnosis of mental illness – something that carries considerable stigma in Yoruba culture.

In Ibadan, Nigeria, there are no nursing homes for elderly demented patients and consequently, all demented patients are managed at home by family members. Demented individuals are only brought to hospital for concomitant illnesses such as fevers or pneumonia, and direct treatment of BPSD at home is unusual, although occasionally phenothiazines are prescribed.

In contrast, Jamaicans have access to primary care and specialist physicians, and treatment approaches are similar to those in the USA. There is little non-physician, community-based support. Treatment for the behavioral aspects of BPSD is primarily with milieu therapy (see Module 5), although pharmacotherapy is also used.

As part of the Indianapolis-Ibadan dementia project a caregiver support group led by a physician and nurse has now been established. This support group has been meeting weekly for the past 18 months and, to our knowledge, is the first of its kind in Nigeria. It has been very well received by the caregivers. Observers have been impressed with the level of understanding of the disease process displayed by the caregivers after simple educational presentations. As in Western countries, the major focus of the meetings is on managing the aberrant behaviors associated with AD including

behavioral disturbances. We are encouraged that this is a care model that could be utilized inexpensively in other third world countries.

## **BPSD in México**

### **Background**

Mexican society is a mixture of different cultures. Most Mexican are descendants of the Spanish and native fusions. However within its vast territory, over 60 different native languages are still spoken, each one with its own particular culture and beliefs.

Demographically México is rapidly changing into a country where the children and the young no longer dominate the age structure. The expected growth of our elders is bound to increase almost threefold in the next 20 years, with its concomitant burden to the economy and service delivery for the aged.

Dementia's prevalence in Mexico is very similar to most countries in the world (Gutierrez et al, 2001), but it is conceivable that Vascular Dementia and Mixed Dementias are more common due to the fact that risk factors for vascular disease in general are poorly tackled in the realm of Mexican general health systems.

In 2001, the Mexican Ministry of Health developed a National Plan under the guidance and direction of the new government. The health of the elderly and those that will develop dementia are the top priorities. A National Plan for dementia, within which BPSD management and training take priority, in Spanish, can be accessed at <http://www.ssa.gob/conadic>.

Data from a large epidemiological study not yet published on dementias in Mexico show that BPSD is a main source of concern and burden for caregivers in Mexico City with the following behaviors noted by families as the most important and problematic for them:

- agitated behaviors including aggression
- depression and apathy
- sleeping disorders
- psychotic phenomenology

### **Approaches to management**

- Management has been limited to empiric treatment for BPSD as a whole and generally disregarded as important by primary care physicians and specialists.
- Pharmacological management of agitated behaviors and psychotic symptoms mainly with traditional neuroleptics (haloperidol) or benzodiazepines (diazepam). When the treating physician considered the use of antidepressants, the main choice has been Tricyclics (imipramine) or SSRIs (fluoxetine).
- Hired home help is common. The nurses or assistant nurses hired for this purpose have no educational background on dementing illnesses and occasionally sedate patient with whatever medication they can get hold on.

The National Plan on dementias addresses the severe deficiencies in the management of BPSD in several ways:

- An educational package is being produced for training trainers. It includes the most recent data and research on BPSD. The packages are aimed at primary care level. Physicians, nurses, social workers can become trainers for this material.

- Training courses on BPSD management, using a clear and approved methodology have been established with approval by the National University. In 2001, eight courses were given training 200 nurses. Many of them will be work as assistants in nursing homes, or will be hired by families to provide assistance at the patient's residence. Twelve courses are planed for 2002.
- An educational package is being developed for use with families from a partnership between the Ministry of Health and the Mexican Alzheimer's Association.

## ***Educational training interventions in BPSD***

Educational training interventions in BPSD offer a means of correcting inappropriate behaviors of patients with dementia from different ethnic-cultural backgrounds with associated problems. This approach, developed in Israel by Tropper et al. 1987, improves general affective and emotional states of patients. It enables those dwelling in the community to remain in their home milieu for several years. It helps those institutionalized to better cope with activities of daily living even in their new environment.

The efficacy of educational training interventions in BPSD is highly relevant for countries facing ethnic and acculturation problems of mass immigration, including Germany, Israel, the USA, Canada and Australia. Israel, as an example, is a country of continuous immigration where 94% of the elderly population were not born in Israel and are bi-, tri- or multi-lingual.

Professional groups participating in and studying educational training interventions in BPSD comprise:

- geriatric psychiatrists
- family physicians
- geriatricians
- psychiatrists
- psychologists
- social workers
- public nurses
- occupational therapists
- staff in geriatric day centers and senior citizen centers
- family members
- volunteers.

Educational training interventions in BPSD have been, and continue to be, applied as a multi-disciplinary approach in various stages of dementia and related disorders. In the current format, educational training interventions in BPSD are oriented towards four symptoms encountered in the demented elderly:

In the behavioral domain:

- wandering
- confusion

In the cognitive domain:

- prosopagnosia
- confabulation

Aims of educational training interventions in BPSD:

- To improve knowledge and understanding of the topic; for example, the typology of wandering in dementia (pottering; trailing; checking; aimless wandering directed towards an appropriate purpose; inappropriate frequent walking towards inappropriate purpose; night-time wandering; attempts to leave the home; excessive activity). See example below.
- To identify needs and develop culturally appropriate professional skills in those who will promote and perform this intervention and training
- To develop a training initiative for caregivers and patients' relatives
- To organize 'training and education days' in the main cities, with the aim of ensuring a rational, quick education program
- To recruit participants to take part in training courses
- To organize 'educational support groups' which will also contribute to the program and communicate with elderly patients in their native language
- To organize local meetings within regions.

## ***Implementation of educational training interventions in BPSD***

Educational training interventions in BPSD in the Israeli program utilize a range of approaches:

- information gathering
- illustrative case studies
- videos
- group discussions
- questionnaires
- suggested reading
- integration into every patient's care plan
- special educational materials (e.g., pamphlets, reminders, essential guidelines, short booklets, maps, tables and figures)
- physical activities
- participation in memory clinics' activities.

Educational training interventions in BPSD are used directly with patients, individually or in group settings, with results that appear to be rewarding. A uniformly structured approach is used in the patient's native language and not necessarily in the official language of the country. Trainers are therefore expected to be fluent in the native tongue of the cultural ethnic groups of elderly patients (e.g., Russian for elderly immigrants who came to Israel from the former Soviet Union)

Educational training interventions in BPSD include special thematic topics, such as Direction – Showing Road Maps, which aim to stimulate remaining strengths, once again taking into account the cultural and ethnic background of the patient.

Educational training interventions in BPSD have been well received by caregivers. They acknowledge that the approach represents an inexpensive and efficient intervention which:

- ameliorates patients' behaviors
- improves patients' activities of daily life
- reduces caregivers' frustration and stress
- gives family members the feeling of being helpful in the treatment of their close and beloved relatives.

An example of educational training interventions in wandering (see also Module 5), which is printed and distributed in Hebrew, Russian and Romanian, is shown in the box below.

### **Essential guide to Educational Training Interventions – an example for managing wandering behavior**

Wandering is a lengthy period of purposeless, disoriented movement without awareness of one's behavior. This is a common behavioral and topographic memory disorder beginning with difficulties of orientation within a patient's apartment or house and culminating in states in which wandering patients are no longer able to find their way back home.

The essential guide provides guidelines for patients, their families and geriatric institutions with ways to prevent and cope with wandering:

- educate family members, caregivers, staff members (see 'Aims of educational training interventions')
- diagnose, differentiate and eliminate other disorders that cause wandering:
  - acute medical illnesses
  - drug actions and interactions
  - avoidance of being alone
  - navigational disability
  - diurnal rhythm disturbances

**Essential guide to Educational Training Interventions – an example for managing wandering behavior** (continued)

- faulty goal-directed behavior
  - excess activity
  - separation anxiety
- milieu therapy oriented towards optimal behavior (home and institutional management)
- initiate diverse activities in various settings:
  - community centers
  - day hospitals
  - homes for the elderly
  - geriatric hospitals
  - senior citizen centers
  - memory clinics: topographic memory skills training
- secure an environment with an adequate visual zone, enabling the patient to recognize anything of importance, such as:
  - the toilet/bathroom
  - the kitchen/dining room
  - doors
  - the bedroom
- install road, stop and explanatory directional signs in the immediate surroundings (garden, neighborhood, etc.)
- program 'planned wandering' guided by a relative or caregiver, who is familiar with the patient's native or mostly spoken language, and all within a safe environmental frame
- supply patients with easily recognizable identification signs:
  - bracelets
  - tags
  - clothing labels
- compile (for police offices) a database of patients who might get lost in different regions where patients are living (i.e., wandering registries)
- notify neighbors, Mogen David Adom (the Israeli equivalent of the Red Cross) and other services of any patient at risk.

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