

# 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.

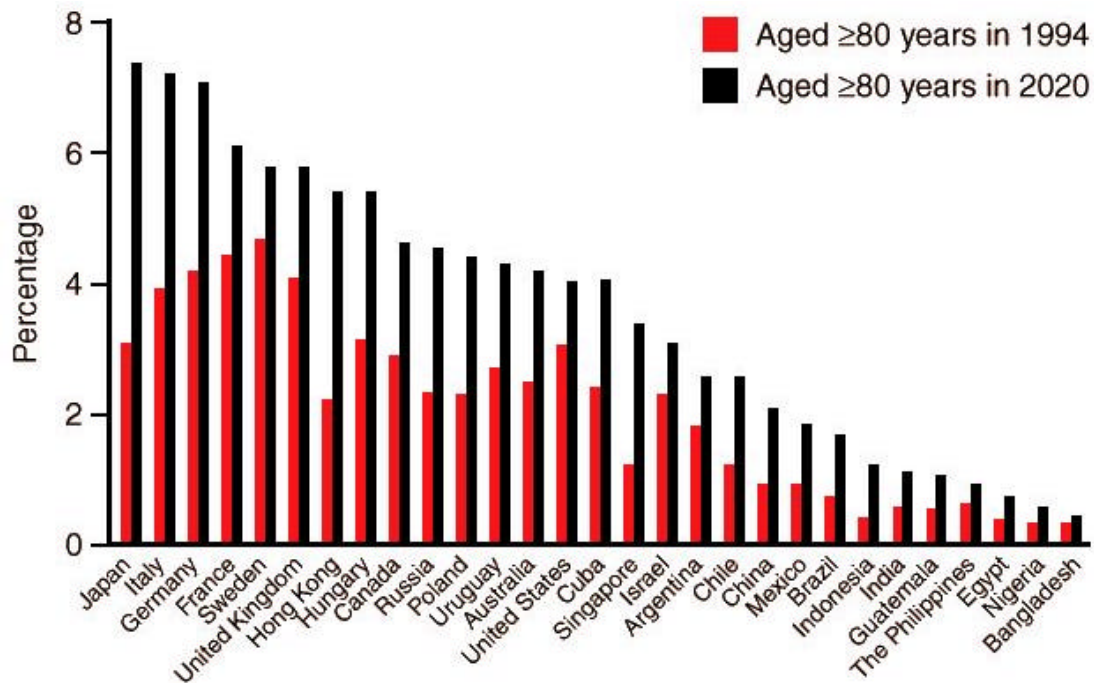


Figure 1. Estimations of the increasing size of the elderly population

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)
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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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