

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



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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>	<b>Verbally 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>	<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>	<b>Verbally 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>	<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.

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- 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.
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### **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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