The IPA Complete Guides to
Behavioral and Psychological Symptoms of Dementia

Specialists • Primary Care Physicians • Nurses
The BPSD Educational Pack was initially produced by the International Psychogeriatric Association (IPA) under an educational grant provided by Janssen-Cilag and Organon (1998, 2002). The 2010, 2012 and 2015 revisions to The IPA Complete Guides to BPSD – Specialists Guide were completed without sponsorship. The opinions expressed herein 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.

Preface

The world’s population is aging rapidly, and with it is coming a significant increase in the number of older people with dementia. This increase presents major challenges for the provision of healthcare generally and for dementia care in particular, for as more people have dementia, there will be more people exhibiting behavioral and psychological symptoms of dementia (BPSD).

BPSD exact a high price from both the patient and the caregiver in terms of the distress and disability they cause if left untreated. BPSD is recognizable, understandable and treatable. The recognition and appropriate management of BPSD are important factors in improving our care of dementia patients and their caregivers, and is central to the development of The IPA Complete Guides to BPSD.

The IPA Complete Guides to BPSD provide a comprehensive overview of the presentation and causes of BPSD, offering constructive guidance on treatment interventions, both pharmacologic and non-pharmacologic, along with information on caregiver education and support.

The IPA Complete Guides to BPSD – Specialists Guide was revised in 2015, based on the BPSD Educational Pack that was originally distributed in 1998 and updated in 2002 and in 2010. Further revisions in 2010 were based upon literature reviews by the contributors. Module 8: Long-term care, was added in 2012.

This guide draws on material presented at the consensus conferences of the International Psychogeriatric Association (IPA) Task Force on Behavioral Disturbances of Dementia (now the IPA Behavioral and Psychological Symptoms of Dementia Shared Interest Forum), held in the Spring of 1996, and the BPSD Update Conference in 1999.

Building on these significant forums, IPA has developed The IPA Complete Guides to Behavioral and Psychological Symptoms of Dementia (BPSD). As described in detail in the following pages, this series of three resource guides – Specialists Guide, Nurses Guide and Primary Care Physicians Guide – specifically addresses issues that are central to each perspective of care for the geriatric mental health patient, recognizing that each professional has a unique role and opportunity to provide care and support to the patient and caregiver.

This guide, The IPA Complete Guides to Behavioral and Psychological Symptoms of Dementia (BPSD) – Specialists Guide, is the most comprehensive in the series, with eight modules of extensive information that is of great value to all those in the geriatric healthcare profession, including physicians, nurses, psychologists, occupational therapists, social workers and others.

We suggest that readers make use of the reference and recommended reading lists provided in this document. Also, we especially hope the material will contribute to the improved management of dementia patients with BPSD and reduce some of the stress experienced by their caregivers and families.

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The IPA Complete Guides to BPSD

The only resource you need for all the members of your team!

It is increasingly important that all professionals involved in the care and treatment of patients exhibiting signs of dementia have a thorough understanding of the Behavioral and Psychological Symptoms of Dementia (BPSD) and are provided with the best possible resources to guide them in developing effective courses of treatment.

It is for that need that the International Psychogeriatric Association (IPA) developed The IPA Complete Guides to BPSD which, although helpful to all geriatric healthcare providers, was prepared with a view toward the different perspectives of the many professions that encounter patients with BPSD.

To address your practice needs, The IPA Complete Guides to BPSD is designed to serve as a reference tool or as a training resource. When used for training, the individual guides of The IPA Complete Guides to BPSD series, as well as each module contained within The IPA Complete Guides to BPSD – Specialists Guide, can be used alone or together in a tailored approach to create your own customized program.

The IPA Complete Guides to BPSD is offered exclusively in electronic form. The advantages of a downloadable version include—

- Lower cost to you than a printed version
- Regular updating ensures you have the most recent information
- Easy to access and use anytime and anywhere you are around the world

The IPA Complete Guides to BPSD – Specialists Guide is a comprehensive compilation of eight modules detailing the presentation and causes of BPSD, constructive guidance on pharmacological and non-pharmacological treatment interventions, and information on caregiver education and support. This is the most extensive in the Guides series, and while helpful for all geriatric healthcare professionals, it is especially instructive for geriatric mental healthcare specialists: physicians, nurses, psychologists, occupational therapists, social workers and others.

The Modules—

- Module 1 – An introduction to BPSD
- Module 2 – Clinical issues
- Module 3 – Etiology
- Module 4 – Role of family caregivers
- Module 5 – Non-pharmacological treatments
- Module 6 – Pharmacological management
- Module 7 – Cross-cultural and transnational considerations
- Module 8 – Long-term care
The IPA Complete Guides to BPSD

Each module includes an in-depth discussion and analysis of its subject area and concludes with a reference and recommended reading list. The content of The IPA Complete Guides to BPSD – Specialists Guide is designed to contribute to the improved management of dementia patients with BPSD and reduce some of the stresses experienced by caregivers and families of dementia patients.

The IPA Complete Guides to BPSD – Nurses Guide is intended for use by nurses and other professionals involved in nursing care to aid in the study and management of patients with BPSD, and is not for use by patients and their caregivers. The Nurses Guide focuses on the unique aspects involved in nursing, including care approaches and nursing interventions specific to BPSD, and the need to provide support to formal and informal caregivers. This guide should be seen as a complement to The IPA Complete Guides to BPSD – Specialists Guide, a more in-depth resource with its many different modules intended for all those healthcare professionals who have specialized in geriatric mental healthcare.

The IPA Complete Guides to BPSD – Primary Care Physicians Guide was written for primary care physicians, as many times they are the first point of contact for patients and their caregivers. In that role, it is vital that physicians and their staff are familiar with clinical manifestations and management of BPSD. This Guide is a valuable resource for the identification and early diagnosis of dementia that is so critical for patients and their caregivers. It is intended as a complement for Primary Care Physicians to The IPA Complete Guides to BPSD – Specialists Guide.

The IPA Complete Guides to BPSD, individually and as a series, provide the needed insight to help with early diagnosis and care for the patient and caregiver. With a disease that affects not just the patient, but also the family and the greater community and social systems, The IPA Complete Guides to BPSD series helps support all geriatric healthcare providers with both broad and specific information and care guidelines.

The International Psychogeriatric Association is committed to advancing geriatric mental health around the world through the creation of comprehensive and practical resources like The IPA Complete Guides to BPSD series. If you have a need to use The IPA Complete Guides to BPSD series in a language other than English, please contact the IPA Secretariat at the address listed on the acknowledgements page of this document to arrange a translation.
Acknowledgments

The production of *The IPA Complete Guides to Behavioral and Psychological Symptoms of Dementia (BPSD) – Specialist’s Guide* has been made possible through the concerted effort of a number of experts in the field of dementia and associated behavioral and psychological symptoms.

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**About IPA**

The *International Psychogeriatric Association* (IPA), founded in 1982, is a unique and diverse professional healthcare community promoting better geriatric mental health—across disciplines, across borders, and across geriatric issues. Psychiatrists, scientists, neurologists, geriatricians, primary care physicians, epidemiologists, nurses, psychologists, occupational therapists, social workers, and many other healthcare professionals come to the IPA community from all over the globe to discuss, learn, share, and research information about behavioral and biological aspects of geriatric mental health. IPA promotes research and education, facilitates an international exchange of ideas on psychogeriatric issues, and fosters cross-cultural understanding of the latest developments in the field.

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# Abbreviations in BPSD

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<td>Antecedents Behavior Consequences</td>
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<td>AD</td>
<td>Alzheimer’s disease</td>
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<td>ADAS-cog</td>
<td>Alzheimer’s Disease Assessment Scale (cognitive portion)</td>
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<td>ADCS</td>
<td>Alzheimer’s Disease Cooperative Study</td>
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<td>ADI</td>
<td>Alzheimer’s Disease International</td>
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<td>ADL</td>
<td>Activities of Daily Living</td>
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<td>ADRC</td>
<td>Alzheimer’s Disease Research Center</td>
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<td>ALMA</td>
<td>Association Against Alzheimer’s Disease and Related Disorders of Argentina</td>
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<td>APOE</td>
<td>Apolipoprotein E</td>
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<td>ARDSI</td>
<td>Alzheimer’s and Related Disorders Society of India</td>
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<tr>
<td>BEHAVE-AD</td>
<td>Behavioral Pathologic Rating Scale for Alzheimer’s disease</td>
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<td>BPSD</td>
<td>Behavioral and Psychological Symptoms of Dementia</td>
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<tr>
<td>CAM</td>
<td>Confusion Assessment Method</td>
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<td>CAMDEX</td>
<td>Cambridge Examination for Mental Disorders of the Elderly</td>
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<td>CASI</td>
<td>Cognitive Abilities Screening Instrument</td>
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<td>CATIE-AD</td>
<td>Clinical Antipsychotic Trials of clinical effectiveness—Alzheimer’s disease</td>
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<td>CBI</td>
<td>Caregiver Burden Inventory</td>
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<td>CBT</td>
<td>Cognitive Behavioral Therapy</td>
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<td>CDR</td>
<td>Clinical dementia rating</td>
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<td>CERAD</td>
<td>Consortium to Establish a Registry for Alzheimer’s Disease</td>
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<td>CERAD-BRSD</td>
<td>Behavior Rating Scale for Dementia of the Consortium to Establish a Registry for Alzheimer’s Disease</td>
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<td>ChAT</td>
<td>Choline acetyltransferase</td>
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<td>CIDI</td>
<td>Composite International Diagnostic Interview</td>
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<td>CIND</td>
<td>Cognitive Impaired Not Demented</td>
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<td>CMAI</td>
<td>Cohen-Mansfield Agitation Inventory</td>
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<td>COMT</td>
<td>Cathecol-O-methyltransferase</td>
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<td>CSDD</td>
<td>Cornell Scale for Depression in Dementia</td>
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<td>CSID</td>
<td>Community Screening Instrument for Dementia</td>
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<td>DAT</td>
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<td>DBDS</td>
<td>Dementia Behavior Disturbance Scale</td>
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<td>DLB</td>
<td>Dementia with Lewy bodies</td>
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<td>DIS</td>
<td>Diagnostic Interview Schedule</td>
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<td>DSM-IV</td>
<td>Diagnostic and Statistical Manual of Mental Disorders (fourth edition)</td>
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<td>ECT</td>
<td>Electroconvulsive therapy</td>
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<td>EPS</td>
<td>Extrapyramidal side effects</td>
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<td>FTD</td>
<td>Frontotemporal dementia</td>
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### Abbreviations in BPSD

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<td>GDS</td>
<td>Geriatric Depression Scale</td>
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<td>GDS</td>
<td>Global Deterioration Scale</td>
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<td>GMS</td>
<td>Geriatric Mental Status</td>
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<td>GRACE</td>
<td>Genetics, responses, and cognitive enhancers</td>
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<td>HPA</td>
<td>Hypothalamic-pituitary-adrenal</td>
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<td>ICD-10</td>
<td>International Classification of Diseases (tenth revision)</td>
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<td>IPA</td>
<td>International Psychogeriatric Association</td>
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<td>LTC</td>
<td>Long term care</td>
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<td>MCI</td>
<td>Mild cognitive impairment</td>
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<td>MDS</td>
<td>Minimum Data Set</td>
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<td>MHPG</td>
<td>3-methoxy-4-hydroxy-phenylglycol</td>
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<td>MIMIC</td>
<td>Multiple Indicators Multiple Causes</td>
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<td>MMSE</td>
<td>Mini-Mental State Examination</td>
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<td>MPHW</td>
<td>Multi-purpose health workers</td>
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<td>NIA</td>
<td>National Institute on Aging</td>
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<td>NHPS</td>
<td>Nursing Home Behavior Problem Scale</td>
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<td>NINCDS-ADRDA</td>
<td>National Institute of the Neurological and Communicative Disorders and Stroke and the Alzheimer’s Disease-Related Disorders Association*</td>
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<td>NMDA</td>
<td>N-methyl d-aspartate</td>
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<td>NOSIE</td>
<td>Nurses’ Observation Scale for Inpatient Evaluation</td>
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<td>NPI</td>
<td>Neuropsychiatric Inventory</td>
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<td>PAS</td>
<td>Pittsburgh Agitation Scale</td>
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<td>RAGE</td>
<td>Rating Scale for Aggression in the Elderly</td>
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<td>REACH</td>
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<td>RMBPC</td>
<td>Revised Memory Behavior Problem Checklist</td>
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<td>Rowland Universal Dementia Assessment Scale</td>
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<td>Sandoz Clinical Assessment Geriatric Scale</td>
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<td>SSRI</td>
<td>Selective serotonin reuptake inhibitors</td>
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<td>TCA</td>
<td>Tricyclic antidepressants</td>
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<td>VaD</td>
<td>Vascular dementia</td>
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<td>WHO</td>
<td>World Health Organization</td>
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<td>ZBI</td>
<td>Zarit Caregiver Burden Interview</td>
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* Now known as the Alzheimer’s Association
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MODULE 1
An introduction to BPSD

The IPA Complete Guides to Behavioral and Psychological Symptoms of Dementia
## 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 older people with Alzheimer’s disease (AD) and other dementias is now occurring.

- Dementia is associated with progressive cognitive decline, 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 identifying and treating BPSD

The aging of the world population

The number of older people in the world is rising rapidly. For example, in 2000, there were 600 million people aged 60 and over; it is estimated there will be 1.2 billion by 2025 and 2 billion by 2050. In 2009 about two thirds of older people were living in the developing world, and by 2025 there will be 75%—a reflection of the improvements in healthcare and nutrition that are enjoyed by much of the world’s population in the second half of the twentieth century. In the developed world, the very old (age 80+) is the fastest growing population group (World Health Organization, 2009).

Figure 1.1: Estimations of the increasing size of the elderly population
As these numbers increase (Figure 1.1), there will be a dramatic rise in the number of people with dementia. This increase will be disproportionately higher in low- and middle-income countries than in high-income countries. The 2009 World Alzheimer Report estimated that there were 35.6 million people with dementia in 2010, the numbers nearly doubling every 20 years, to 65.7 million in 2030 and 115.4 million in 2050. The majority of people with dementia currently live in low- and middle-income countries (58% in 2010) and this will rise to 71% by 2050 (Alzheimer’s Disease International, 2009).

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; Brayne, 2006). The prevalence of dementia has been reported to be between 5% and 8.5% in those over the age of 60 years, while in the very elderly, the prevalence is between 28.7% and 63.9% in those over the age of 90 years (Alzheimer’s Disease International, 2009).

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 implication 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 ‘demence senile’ in 1838, Esquirol noted that it is a condition that 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, particularly visual hallucinations and depression, are seen in Lewy body dementia. The behavioral variant of frontotemporal dementia, as its name implies, has predominant early behavioral changes that can include apathy, altered eating behavior, socially and sexually inappropriate behaviors, irritability and compulsive behaviors.

Consensus definitions of AD have generally included behavioral descriptions. The American Psychiatric Association’s Fifth Edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM5) describes major neurocognitive disorder with or without behavioral disturbance but does not provide a code for the specific type of behavior. 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 neuropathological changes whereas others have focused more on personality contributions 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 of scales developed to evaluate BPSD (see the box below for some examples and this module’s Appendix for a full list).

<table>
<thead>
<tr>
<th>Year</th>
<th>Description</th>
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<tr>
<td>1986</td>
<td>The Cohen-Mansfield Agitation Inventory (CMAI) focused specifically on behaviors such as hitting, pacing and screaming (Cohen-Mansfield et al., 1989; Cohen-Mansfield, 1996).</td>
</tr>
<tr>
<td>1987</td>
<td>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 the delusion that people are stealing things, fear of being left alone and fragmented sleep (Reisberg et al., 1996).</td>
</tr>
<tr>
<td>1994</td>
<td>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).</td>
</tr>
<tr>
<td>1995</td>
<td>The Consortium to Establish a Registry in AD (CERAD) Behavioral Scale focused on both behavioral and psychological symptoms (Tariot et al., 1995; Tariot, 1996).</td>
</tr>
<tr>
<td>2008</td>
<td>The Cambridge Behavioural Inventory—Revised—designed to distinguish FTD from AD and other degenerative dementias (Wear et al, 2008)</td>
</tr>
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</table>

Modern definition of BPSD—a consensus statement

In 1996, the International Psychogeriatric Association (IPA) convened the Consensus Conference on the Behavioral Disturbances of Dementia for two purposes: to review current knowledge on behavioral disturbances of dementia and 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:

The consensus group, consisting of some 60 experts in the field, from 16 countries, produced a statement on the definition of 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 and 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 following box.

<table>
<thead>
<tr>
<th>Behavioral symptoms</th>
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<tr>
<td>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.</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Psychological symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>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.</td>
</tr>
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</table>

The European Alzheimer’s Disease Consortium also noted that the term BPSD is not a unitary concept and recommended that it should be divided into several or more groups of symptoms (e.g., apathy, mood/agitation, psychosis) each possibly reflecting a different prevalence, course over time, biological correlate and psychosocial determinants (Robert et al., 2005). One grouping based upon factor analysis of the CMAI suggested four groups—aggressive behavior, physically non-aggressive behavior, verbally agitated behavior, and hiding and hoarding (Rabinowitz et al., 2005). A Multiple Indicators Multiple Causes (MIMIC) model identified four factors—psychosis, moods, agitation, and behavioral dyscontrol (Proitsi et al., 2009). Clearly more research is required to better characterize BPSD syndromes, although current knowledge about variations of BPSD between individuals and psychosocial circumstances emphasizes the importance of a tailored approach to treatment and care. The clinical presentation of BPSD is covered in detail in Module 2.

**Frequency and impact of BPSD**

BPSD can result in suffering, premature institutionalization, increased costs of care, and significant loss of quality-of-life for people with dementia and their families and caregivers (Finkel et al., 1996). A number of studies looking at the occurrence of BPSD in nursing home and community populations have found these symptoms to occur in up to 97% of patients. The Medical Research Council Cognitive Function and Ageing Study in England and Wales found that 11 of 12 symptoms of BPSD were more common in 587 participants with dementia than
in 2,050 participants without dementia—the exception being sleep problems (Savva et al., 2009). The Cache County study has reported the point- and 5-year-period prevalence of BPSD on the Neuropsychiatric Inventory (NPI) in an incident sample of 408 dementia participants (Steinberg et al., 2008). Details of the study are presented in Table 1.1. BPSD tend to persist; for example, at 18-month follow-ups in the Cache County study, delusions persisted in 65.5% of individuals, depression in 58.3%, and aberrant motor behavior in 55.6% (Steinberg et al., 2004).

Table 1.1: Point and 5-year Prevalence of BPSD in the Community as measured by the Neuropsychiatric Inventory (NPI)

<table>
<thead>
<tr>
<th>NPI BPSD items</th>
<th>Point Prevalence at Baseline (%)</th>
<th>Five-year period prevalence (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Delusions</td>
<td>18</td>
<td>60</td>
</tr>
<tr>
<td>Hallucinations</td>
<td>10</td>
<td>38</td>
</tr>
<tr>
<td>Agitation/Aggression</td>
<td>14</td>
<td>45</td>
</tr>
<tr>
<td>Depression/Dysphoria</td>
<td>29</td>
<td>77</td>
</tr>
<tr>
<td>Apathy/Indifference</td>
<td>20</td>
<td>71</td>
</tr>
<tr>
<td>Elation/Euphoria</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Anxiety</td>
<td>14</td>
<td>62</td>
</tr>
<tr>
<td>Disinhibition</td>
<td>7</td>
<td>31</td>
</tr>
<tr>
<td>Irritability/Lability</td>
<td>20</td>
<td>57</td>
</tr>
<tr>
<td>Aberrant Motor Behavior</td>
<td>7</td>
<td>52</td>
</tr>
<tr>
<td>Any Symptom</td>
<td>56</td>
<td>97</td>
</tr>
</tbody>
</table>

(Steinberg et al., 2008, reproduced with permission)

Rates of BPSD are high in nursing homes around the world regardless of which behavioral scales are used. For example, in Australia 92% of nursing home residents were reported to have at least one type of BPSD as measured by the BEHAVE-AD (Brodaty et al., 2001), in the Netherlands 81% had clinically significant neuropsychiatric symptoms on the NPI-NH, and 85% showed at least one symptom of agitation on the Cohen-Mansfield Agitation Inventory (CMAI) (Zuidema et al., 2007). In Norway 84% of residents had clinically significant neuropsychiatric symptoms on the NPI (Selbæk et al., 2008); and in the United States 69% had behavioral symptoms on the Patient Assessment Instrument when residents with comorbid psychiatric disorders were excluded (McCarthy et al., 2004). More details of specific behaviors as measured by the BEHAVE-AD and CMAI are noted in Tables 1.2 and 1.3.
### Table 1.2: Prevalence of BPSD in 11 Sydney Nursing Homes

<table>
<thead>
<tr>
<th>BEHAVE-AD BPSD items</th>
<th>Prevalence (%)</th>
</tr>
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<tbody>
<tr>
<td>Delusions</td>
<td>54</td>
</tr>
<tr>
<td>Hallucinations</td>
<td>33</td>
</tr>
<tr>
<td>Psychosis (Delusions + Hallucinations)</td>
<td>60</td>
</tr>
<tr>
<td>Activity Disturbance</td>
<td>53</td>
</tr>
<tr>
<td>Aggression</td>
<td>77</td>
</tr>
<tr>
<td>Behavioral Disturbance (Activity Disturbance + aggression)</td>
<td>82</td>
</tr>
<tr>
<td>Diurnal Disturbance</td>
<td>47</td>
</tr>
<tr>
<td>Affective Disturbance</td>
<td>60</td>
</tr>
<tr>
<td>Anxiety and Phobias</td>
<td>69</td>
</tr>
<tr>
<td>BEHAVE-AD Total</td>
<td>92</td>
</tr>
</tbody>
</table>

(Brodaty et al., 2001; reproduced with permission)

### Table 1.3: Prevalence of BPSD in 59 Dutch Dementia Special Care units

<table>
<thead>
<tr>
<th>CMAI BPSD Items with prevalence ≥ 10%</th>
<th>Prevalence (%) at least weekly</th>
</tr>
</thead>
<tbody>
<tr>
<td>General restlessness</td>
<td>44</td>
</tr>
<tr>
<td>Cursing or verbal aggression</td>
<td>33</td>
</tr>
<tr>
<td>Constant request for attention</td>
<td>32</td>
</tr>
<tr>
<td>Negativism</td>
<td>31</td>
</tr>
<tr>
<td>Repetitious sentences/questions</td>
<td>30</td>
</tr>
<tr>
<td>Pacing</td>
<td>29</td>
</tr>
<tr>
<td>Performing repetitious mannerisms</td>
<td>28</td>
</tr>
<tr>
<td>Complaining</td>
<td>26</td>
</tr>
<tr>
<td>Grabbing</td>
<td>24</td>
</tr>
<tr>
<td>Making strange noises</td>
<td>20</td>
</tr>
<tr>
<td>Inappropriate robing/disrobing</td>
<td>18</td>
</tr>
<tr>
<td>Handling things inappropriately</td>
<td>18</td>
</tr>
<tr>
<td>Get to different place</td>
<td>16</td>
</tr>
<tr>
<td>Hitting</td>
<td>13</td>
</tr>
<tr>
<td>Screaming</td>
<td>13</td>
</tr>
<tr>
<td>Hoarding things</td>
<td>12</td>
</tr>
<tr>
<td>Hiding things</td>
<td>10</td>
</tr>
</tbody>
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(Zuidema et al., 2007; reproduced with permission)
The 10/66 Dementia Research Group pilot studies in low- and middle-income countries from Latin America, India, China, and South East Asia, and Nigeria found that 71% of carers reported at least one problem behavior. The people with dementia were also assessed, and significant psychological symptoms were detected in 50% (Ferri et al., 2004)

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.

Untreated BPSD contribute to:

- Premature institutionalization (Colerick and George, 1986; Morriss et al., 1990; Steele et al., 1990; O’Donnell et al., 1992; de Vugt et al., 2005)
- Increased financial cost (Cohen-Mansfield, 1995; Herrmann et al., 2006)
- 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; Hinton et al., 2008), 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

Since the 1990s there has been increased interest in specific therapies for BPSD for several reasons:

- BPSD are recognized as major sources of burden for caregivers of people 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.

There are many reasons why good research data were previously lacking. Older people with dementia were considered a ‘difficult’ study population because of their age, frailty, and the nature of their illnesses. Until the 1990s there were no good methods to assess individuals with dementia. Subsequently, governments, the pharmaceutical industry, and research foundations have become interested in BPSD. Efforts to measure the outcome of treatment in terms of quality of life and cost-effectiveness are increasing. The research has yielded mixed results, confirming that antipsychotic drugs have modest efficacy in the treatment of agitation, aggression, and psychosis associated with dementia but with an increased risk of cerebrovascular adverse events and mortality. There are no proven alternative psychotropic agents for BPSD, although many are being investigated (Jeste et al., 2008). There are also some promising indications that non-psychotropic agents such as analgesics might be effective for BPSD (Husebo et al., 2011) (See Module 6).
Similarly, while there are some promising non-pharmacological treatments for BPSD such as aromatherapy, ability-focused carer education, preferred music therapy, and muscle relaxation training, effect sizes are modest, and there is still considerable need for more research (O’Connor et al, 2009a, b). (See Module 5).

While some of these BPSD treatment outcome studies have yielded disappointing results, the importance of tailoring pharmacological and/or non-pharmacological interventions to fit the needs of individuals with behaviors that have complex multifactorial etiologies has become clearer (Meares and Draper, 1999; Bird et al., 2007). In addition, non-pharmacological interventions should generally be employed before pharmacotherapy. In a 4-week open-label brief psychosocial intervention that was employed as the first stage of a RCT of the treatment of clinically significant agitation in Alzheimer’s disease, 43% of the participants improved by 30% on the CMAI (Ballard et al., 2009). The challenge is to better identify which interventions work best for specific behaviors in individuals in various contexts.

Quality-of-life assessment

Recently, there have been attempts to measure quality of life in older 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 older medically ill people with dementia, 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, courses, 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 people with dementia, as well as the availability of measurement scales specifically developed for this population. Research resources are unevenly distributed and unavailable in many countries. More research is needed to ensure a strong and productive research program.

Research now needs to address the following areas:

- Development of cross-culturally applicable methods for the assessment of BPSD
- Further exploration of the relationship of types of BPSD to the environments in which they occur
- Understanding of the etiological biological and psychological substrates of types of BPSD
- Longitudinal evaluation of the incidence and prevalence of BPSD in different types of dementia
- Determination of the clinical and social impact of BPSD on the patient, family, healthcare professionals, healthcare systems, and society
- Development of a well-defined profile of treatment methods with specific reference to different types of BPSD and the response of those BPSD to non-pharmacological and pharmacological interventions

IPA educational programs for BPSD

The continuing discussion and need to define and understand BPSD in patients has led to the formation of IPA's Shared Interest Forum on BPSD. The mission of the BPSD Special Interest Group is “the promotion of research, training, and dissemination of information on behavioral and psychological symptoms of dementia [BPSD] to healthcare professionals and caregivers.”

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 the following:

- Publication in journals
- Establishment of an international speakers’ bureau slides
- An internet web site
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)

Behavioral Pathology in Alzheimer’s Disease Rating Scale (BEHAVE-AD)

Blessed Dementia Scale

Brief Agitation Rating Scale (BARS)

Cambridge Behavioural Inventory—Revised

Caretaker Obstreperous Behavior Rating Assessment (COBRA)

CERAD Behavior Rating Scale for Dementia

Cohen-Mansfield Agitation Inventory (CMAI)

Cornell Scale for Depression in Dementia (CSDD)

Dementia Behavior Disturbance Scale (DBD)
Dementia Mood Assessment Scale (DMAS)

Dysfunctional Behavior Rating Instrument (DBRI)

Global Assessment of Psychiatric Symptoms (GAPS)

Gottfries-Bråne-Steen Scale

Irritability/Apathy Scale

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

Neurobehavioral Rating Scale

Neuropsychiatric Inventory (NPI)

Neuropsychiatric Inventory—Nursing Home Version (NPI-NH)

Pittsburgh Agitation Scale

Revised Memory and Behavior Problems Checklist
Sandoz Clinical Assessment—Geriatric (SCAG)

Self-Psychology Rating Scale

**References and recommended reading**


Esquirol, J.E.D. *Des Maladies Mentales* 1938.


MODULE 2
Clinical issues

The IPA Complete Guides to Behavioral and Psychological Symptoms of Dementia

Specialists Guide

Specialists • Primary Care Physicians • Nurses
# 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

And 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
- Repetitive questioning
- Cursing
- Shadowing (stalking)
- Apathy

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., (2000) reported that people with dementia had over 40 times the rate of behavioral disturbance than did the rest of the population, 61% of people with dementia had at least one behavioral disturbance and 31% had severe levels of BPSD (defined as an NPI score of ≥ 6). A more recent study from the UK compared 587 patients with dementia living in the community with 2,050 non-demented controls. The study found that “BPSD affect nearly all dementia patients.” They also noted that all BPSD were more common in dementia patients versus controls except sleep problems, and that BPSD symptoms often co-occur, e.g. depression and anxiety. Psychosis occurred more frequently with declining
cognition and anxiety and depression were more common in younger dementia patients (Savva et al., 2009). The average prevalence of at least one BPSD symptom in residents with dementia living in long-term care facilities is 82%, with agitation and apathy being most prevalent of all BPSD symptoms (Selbaek et al., 2013). Large proportions of residents with dementia living in long-term care facilities were found to have exhibited one or more of four kinds of behavioral symptoms in the previous week (1) physically aggressive behaviors (e.g., hitting, kicking); (2) verbally aggressive behaviors (e.g., cursing); (3) physically non-aggressive behaviors (e.g., pacing); and (4) resistance to care (e.g., resistance with personal care) (IOM 2012). Depression and psychotic symptoms often accompany these behaviors. Resident-to-staff and resident-to-resident sexual aggression is also prevalent in long-term care facilities (Rosen et al., 2010).

Characteristics of BPSD are listed in Table 2.1. A historical review of the nosology or classification of BPSD is presented in this Module’s Appendix 1. A variety of instruments have been developed to quantify BPSD, and theories behind existing rating scales are reviewed in this Module’s Appendix 2.

### Table 2.1: Characteristics of BPSD

<table>
<thead>
<tr>
<th>Psychotic symptoms</th>
<th>Misidentification syndromes</th>
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</thead>
<tbody>
<tr>
<td>Apathy</td>
<td>Aggressivity</td>
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<tr>
<td>Delusions</td>
<td>Depression</td>
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<tr>
<td>Anxiety</td>
<td>Wandering</td>
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<td>Hallucinations</td>
<td>Sundowning</td>
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<tr>
<td>Agitation</td>
<td>Sexual</td>
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<tr>
<td>- Verbal</td>
<td>Impulsive</td>
</tr>
<tr>
<td>- Physical</td>
<td>Catastrophic reactions</td>
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</tbody>
</table>

### 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 prevalent neuropsychiatric symptoms in 123 hospice-eligible patients with advanced dementia residing in a nursing home were agitation or aggression (50%), depression (46%), and withdrawal/lethargy (43%) (Kverno et al., 2008). Some BPSD are more persistent than others. For example, one study has shown that agitation is the most enduring behavioral symptom in patients with mild to moderate AD over a five-year observation period (Devanand et al., 1997).

### Variation with type of dementia

More than 70 conditions can cause dementia in the elderly (Cohen et al., 1993). By far the most common is Alzheimer’s disease (AD) (greater than 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 (DLB) 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. Using the Revised Consensus Criteria for DLB, recent studies have found DLB to be the second most common cause of progressive dementia after AD (Aarsland et al. 2008).

Some studies have found few differences between the prevalence of BPSD in AD and VaD (Cohen et al., 1993; Tariot and Blazina, 1994; Thompson et al., 2010); others have reported a higher rate of delusions in AD and a higher rate of depression in VaD (Lyketsos et al., 2000). Overall, depression, emotional lability, and apathy seem to be more common in VaD versus AD and psychosis less common. Depression has an especially strong relationship with VaD (O’Brien et al., 2003). In the study by Cohen, et al. (1993), patients with mixed AD and VaD had the 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. More recently, a study by Staekenborg et al., (2010), found different rates of BPSD in small vessel disease VaD compared to large vessel disease VaD. Small vessel VaD showed more apathy, aberrant motor behavior and hallucinations. Large vessel VaD had higher rates of agitation/aggression and euphoria. This study found BPSD in 92% of the total VaD population with 65% having apathy, 45% depression, 42% irritability and 40% showing agitation/aggression.

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). A recent prospective, community-based, autopsy-confirmed study of 148 patients with dementia found 27 to have had visual hallucinations. Those with visual hallucinations were younger at intake and more likely to have agitation, delusions and apathy. Seventy-eight percent of those with visual hallucinations were found to have Lewy body pathology—of these, 59% also had DAT at autopsy (Tsuang et al., 2009).

Parkinson’s disease dementia (PDD) is increasingly being recognized with recently proposed diagnostic guidelines (Goetz et al., 2008). PDD presents with prominent executive function disturbance in a patient with at least a two-year history of Parkinson’s disease (PD). Most often the dementia in PD is seen eight or more years after PD onset. PDD has less prominent memory disturbance early on and a higher association with depression than AD (Robottom and Weiner, 2009).

Frontotemporal dementia (FTD) has been associated with higher incidences of many symptoms (Mendez et al., 2008) including impulsivity (Lindau et al., 1998), compulsive behaviors (Rosso et al., 2001), hypersexuality (Cummings and Duchen, 1981) and verbal outbursts (Mendez et al., 1998). FTD is significantly associated with increased caregiver distress (Mourik et al., 2004). Emergence of artist abilities has been associated with left temporal involvement in frontotemporal dementia (Miller et al., 1998). The anatomic distribution of asymmetric atrophy in frontotemporal dementia has been correlated with specific BPSD (Snowden 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 Duchen, 1981). A recent study has found that BPSD occur in all stages of Huntington’s disease; often, behavioral...
problems arise prior to onset of motor symptoms; apathy is related to disease severity, while depression and irritability are not (Kingma et al., 2008). A 25-year analysis of the literature on Creutzfeldt-Jakob disease relative to BPSD found that 80% demonstrated BPSD within the first 100 days of the illness with 26% having BPSD at the time of presentation. The most common symptoms were sleep disturbance, psychosis, and depression. Psychiatric symptoms often preceded formal diagnosis (Wall et al., 2005).

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

**Specific symptomatology: psychological**

**Psychotic symptoms**

A review of 55 studies published from 1990-2003 found that psychosis has been reported in 41% of patients with AD, with 36% having delusions and 18% having hallucinations. African American or black ethnicity and more severe cognitive impairment were associated with higher rates of psychosis and the presence of psychotic symptoms was associated with a more rapid rate of cognitive decline in AD. The intensity of psychotic symptoms often diminished after one-year follow-up (Ropacki et al., 2005).

**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). One study (Omar et al., 2009) looked at delusions in frontotemporal lobar degeneration. Delusions were seen in 14% of patients and were often seen early in the course of the disease, were prominent, and persistent. Paranoid and somatic delusions were most common.

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 person with dementia 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 older people with dementia, 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% to 43% of patients. The ‘delusion of abandonment’ is also relatively common with estimates of its frequency ranging from 3% to 18% of patients (Tariot and Blazina, 1994). As noted above, the ‘delusion of infidelity’ is occasional with frequency estimates ranging from 1% to 9% of patients (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. Gilley et al., (1997) also reported that the presence of delusions predicts the occurrence and frequency of physical aggression with 80% of study participants who showed high rates of physical aggression (i.e. more than one episode per month) also having delusions. A recent study from Taiwan showed that a given dementia patient’s personal history may determine the unique nature of her/his delusions and visual hallucinations (Pai, 2008).

**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 below).

### 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

A study of misidentifications in various dementias found them to be present in 16% of AD patients, 17% of those with DLB, and 0% in FTD and PDD (Harciarek and Kertesz, 2008).
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** is the most common of the delusional misidentification syndromes (Harcarek and Kertesz, 2008). Sometimes called the syndrome of imposters, Capgras syndrome 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 to approve indications for therapy specifically for Psychosis of Alzheimer’s disease. Current efforts are also underway to define psychoses in other dementing illnesses more precisely.
Table 2.2: Proposed Diagnostic Criteria for Psychosis in Alzheimer’s disease

<table>
<thead>
<tr>
<th>Characteristic symptoms</th>
</tr>
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<tbody>
<tr>
<td>Presence of visual or auditory hallucinations, or delusions, or both.</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Primary diagnosis</th>
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</thead>
<tbody>
<tr>
<td>All the criteria for dementia of the Alzheimer type are met.*</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Chronology of the onset of symptoms of psychosis vs onset of symptoms of dementia</th>
</tr>
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<tbody>
<tr>
<td>There is evidence from the history that the symptoms in Criterion A have not been present continuously since prior to the onset of dementia.</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Duration and severity</th>
</tr>
</thead>
<tbody>
<tr>
<td>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.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Exclusion of schizophrenia and related psychotic disorders</th>
</tr>
</thead>
<tbody>
<tr>
<td>Criteria for schizophrenia, schizoaffective disorder, delusional disorder or mood disorder with psychotic features have never been met.</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Relationship to delirium</th>
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<tr>
<td>The disturbance does not occur exclusively during the course of delirium.</td>
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</table>

<table>
<thead>
<tr>
<th>Exclusion of other causes of psychotic symptoms</th>
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<tbody>
<tr>
<td>The disturbance is not better accounted for by another general medical condition or direct physiological effects of a substance (e.g. a drug abuse, a medication).</td>
</tr>
</tbody>
</table>

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

Adapted from Jeste and Finkel (2000)
### Table 2.3: Psychosis of AD compared with Schizophrenia in the elderly

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

Adapted from Jeste and 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 in 10–20% of patients than subsyndromal depression (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 DSM5 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. Families, who have intuitiveness about their loved-one with dementia, may suspect depression when the clinician may not. Depressive disorder should therefore be considered when one or more of the following conditions are noted:
• Acute, unexplained behavior changes
• A pervasive depressed mood and loss of pleasure
• Family suspicion of depression
• Self-deprecatory statements and expressed wishes to die
• A family or personal history of depression prior to the onset of dementia.
• Rapid decline in cognition (Starkstein et al., 2008)

Differential diagnosis of depression in dementia often involves discriminating depression from apathy and pathological affect-crying. 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 et al., 2000). Apathy is present in up to 50% of patients in the early and intermediate stages of AD and other dementias. Apathy may increase with severity of AD (Turro-Garriga et al., 2009) and persistent apathy may be a risk-factor functional decline in AD (Lechowski et al., 2009).

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 or a psycho-stimulant (Padala et al., 2010). Recently, diagnostic criteria for apathy in AD have been proposed (Robert et al., 2009).

Anxiety
Anxiety in dementia may be related to the manifestation of other BPSD or occur independently. Rates of anxiety may be higher in VaD than AD and anxiety decreases in severe dementia (Seignourel et al., 2008). A Canadian study found the prevalence of anxiety disorders in AD and other dementias to be 16% versus 4% in age-matched, non-demented controls (Nabalamba and Patten, 2010). Patients with anxiety and dementia may express previously non-manifest concerns about their finances, future and health (including their memory) and worries about previously non-stressful 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 BPSD, particularly in terms of the burden it places on caregivers. Wandering often results in persons having dementia being admitted to a long-term care facility. It is frequent cause of referral to psychiatric services. Wandering behaviors includes aimless walking and exit seeking/repeatedly attempting to leave the house. Faulty navigational ability, boredom, and anxiety may underlie some wandering behaviors.

**Agitation/Aggression**

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, 2000). Its prevalence in persons having dementia increases with degree of cognitive impairment. Agitation in persons having dementia is a complex phenomenon. Neurobiological changes associated with dementia, comorbid medical factors, psychological, social and environmental factors interacting with premorbid personality influence development of agitation. Aberrant motor behavior may be more prevalent and severe in AD compared to VaD (Fernandez-Martinez et al., 2008). Among patients having vascular dementia, agitation may be more common in patients with large vessel disease compared to small vessel disease (Staekenborg et al., 2009). Cohen-Mansfield Agitation Inventory (CMAI) and Pittsburg Agitation Scale (PAS) are often used in clinical settings besides research settings to assess agitation (Cohen-Mansfield, 1986; Rosen et al., 1994). Four subtypes have been identified using CMAI (listed in Table 2.4).
### Table 2.4: Subtypes of agitation

<table>
<thead>
<tr>
<th>Physically non-aggressive behaviors</th>
<th>Physically aggressive behaviors</th>
</tr>
</thead>
<tbody>
<tr>
<td>• General restlessness/purposeless hyperactivity/ repetitive physical movements</td>
<td>• Hitting</td>
</tr>
<tr>
<td>• Wandering</td>
<td>• Screaming</td>
</tr>
<tr>
<td>• Rumming</td>
<td>• Pushing</td>
</tr>
<tr>
<td>• Repetitive mannerisms</td>
<td>• Scratching</td>
</tr>
<tr>
<td>• Pacing</td>
<td>• Kicking</td>
</tr>
<tr>
<td>• Hiding things</td>
<td>• Biting</td>
</tr>
<tr>
<td>• Inappropriate dressing or undressing</td>
<td>• Grabbing</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Verbally non-aggressive behaviors</th>
<th>Verbally aggressive behaviors</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Constant requests for attention</td>
<td>• Screaming</td>
</tr>
<tr>
<td>• Verbal bossiness</td>
<td>• Cursing</td>
</tr>
<tr>
<td>• Complaining or whining</td>
<td>• Temper outbursts</td>
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Physically and verbally aggressive behaviors are more likely to occur in patients having dementia who have poor social relationships. Verbally aggressive behavior is associated with depression, pain and other health problems. Agitation correlates strongly with irritability, disinhibition and delusions. Agitation and aggression are among the most troublesome BPSD for caregivers and, along with depression and psychosis, are leading predictors of institutionalization (Gaugler et al., 2009).

**Resistiveness to care**

Resistiveness to care is another distinct behavioral syndrome and thus needs to be differentiated from agitation (Volicer et al., 2007). It involves resisting taking medications, activities of daily living (ADL) assistance or eating. It is related to the ability of person having dementia to understand, and thus, increases in prevalence with worsening of cognitive impairment. Resistiveness to care is associated with verbally and physically abusive behavior towards caregivers (Volicer et al., 2009).

**Inappropriate sexual behaviors**

Inappropriate verbal and physical sexual behaviors (also referred to as sexual disinhibition or hypersexuality) involve persistent, uninhibited sexual behaviors directed at oneself or at others. They are prevalent in patients who have dementia. They are profoundly disruptive to caregivers (family and professional) and other individuals in the immediate surroundings. Substantial mental and physical harm can occur, secondary to these behaviors (Guay, 2008). Inappropriate sexual behaviors also pose complex logistical and ethical problems for caregivers (Wallace and Safer, 2009).
Catastrophic reaction

Catastrophic reaction is an acute expression of overwhelming anxiety and frustration—often triggered in persons having dementia by adverse experiences such as frustration with getting dressed, or with paying bills, etc. They are also sometimes referred to as rage reactions. They are typically brief and self-limited, and can be avoided by assigning manageable tasks for the person having dementia. They manifest as sudden angry outbursts, verbal aggression (e.g., shouting and cursing), threats of physical aggression and physical aggression. Delirium, pain, infection and certain medications can also provoke catastrophic reactions.

Sundowning

Sundowning is the occurrence and exacerbation of BPSD in the afternoon or evening. Agitation and sleep disturbances commonly accompany sundowning. Sundowning increases burden of care on caregivers as it often occurs when the staffing in institutional setting is at the lowest levels. The circadian, hormonal, physiological, and environmental correlations with sundowning have been described (Sharer, 2008). AD and other dementias cause disturbances of circadian rhythms and sundowning may be related to a phase delay of body temperature caused by dementing illness (Volicer et al., 2001).

Assessment tools

The use of valid and standardized outcome measures for the assessment of BPSD is critical not only in research settings but also in some clinical settings (e.g., to measure response to antipsychotics or antidepressants). The Neuropsychiatric Inventory (NPI) and the Behavioral Pathology in Alzheimer’s Disease Rating Scale (BEHAVE-AD) are two of the best measures recommended for measuring behavioral disturbances in individuals with dementia (Jeon et al., 2011). These global scales may not be adequate to measure depressive symptoms as they rely primarily on mood symptoms (mainly sadness). Depression specific scales are preferred over these global scales to measure depression. The Cornell Scale for Depression in Dementia (CSDD) is recommended for measuring depression in individuals with advanced dementia who cannot give valid self-report of depressive symptoms (Alexopoulos et al., 1988). The Geriatric Depression Scale (30- and 15-item versions) (GDS) can be used to measure depressive symptoms in individuals with mild dementia (Yesavage et al., 1983).

Delirium: a differential diagnosis from BPSD

Patients who have dementia are at higher risk for developing delirium. Patients who have delirium may experience the behavioral and psychological symptoms seen in dementia. Diagnosing delirium in a cognitively intact patient is fairly straightforward, with the sudden onset of global impairment that is 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 four 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 symptoms 3 or 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
- Altered psychomotor activity and occasionally 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 infection
- Medication
- Malnutrition/dehydration
- Metabolic illnesses (e.g., certain renal or hepatic diseases)
- Changes/stress in the patient’s environment
- Surgery

The following are scenarios that illustrate the varied 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 3A4 isoenzyme.
- Alternative medications which often have psychoactive and anticholinergic properties can trigger delirium, as can eye drops with beta-blocker properties.
- Delirium may result if a person with dementia unknowingly takes medication prescribed for family members or friends.
- 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 patient 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 cognitive 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. Few overall changes were made in the revision of the *DSM-III* (*DSM-III-R*; American Psychiatric Association, 1987), with scant attention paid to the types of symptoms or behaviors often so troubling in managing patients with dementia.

**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). The NINCDS-ADRDA criteria for probable AD did mention depression, insomnia, delusions, illusions, hallucinations, catastrophic reactions (verbal, emotional and physical outbursts) and sexual disorders as associated symptoms of AD.

**DSM-IV and DSM-IV-TR**

The *DSM-IV* (American Psychiatric Association, 1994) and subsequently *DSM-IV-Text Revision (DSM-IV-TR)* (American Psychiatric Association, 2000) criteria for dementia incorporated the multiple cognitive deficits standard of the NINCDS-ADRDA criteria. In *DSM-IV-TR*, greater attention was given to describing associated clinical features, such as problems with perception, mood and emotion, behavior and motor function. When the *DSM-IV* and the *DSM-IV-TR* were 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.

**The DSM5 criteria**

The *DSM5* uses the terms *major neurocognitive disorder* and *minor neurocognitive disorder* to replace the term *dementia* (American Psychiatric Association, 2013). Major neurocognitive disorder criteria are similar to dementia and minor neurocognitive disorder overlaps with mild cognitive impairment. *DSM5* also allows specifying if the cognitive disturbance is with or without behavioral disturbance and to specify severity of major neurocognitive disorder (mild, moderate, severe). Only two neurocognitive disorders in *DSM5* have specific behavioral or psychological symptoms as part of the criteria for their diagnosis. The *DSM5* criteria for major or mild neurocognitive disorder with Lewy bodies specifies recurrent visual hallucinations that are well formed and detailed as one of its three core diagnostic features and rapid eye movement sleep behavior disorder as one of its suggestive diagnostic features. The *DSM5* criteria for behavioral variant of major or mild frontotemporal neurocognitive disorder involves presence...
of three or more of the following five behavioral symptoms: behavioral disinhibition, apathy/inertia, loss of sympathy or empathy, perseverative/stereotyped or compulsive/ritualistic behaviors, and hyperorality. One benefit of not using the term *dementia* is that the associated stigma and resulting emotional distress may be less with the use of *major neurocognitive disorder* as diagnosis.

**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. ICD-10 did not include a designation to characterize patients with BPSD, although subtypes of dementia (delusions, hallucinatory, depressive and mixed) were described.

**Summary**

Although the specifying phrase ‘with behavioral disturbance’ was added to *DSM-IV, DSM-IV-TR,* and now *DSM5,* it is unclear how this term has been used in everyday clinical practice. Neither *DSM5* 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 subtype 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 its measurement or classification is still awaited.

**Appendix 2. Rating scales for BPSD in clinical settings**

In research and clinical settings, several rating scales listed in Table 2.5 are recommended to improve assessment of BPSD and to assess response to treatment (Conn and Thorpe, 2007, Burns et al., 2003). This list is not exhaustive but meant to provide some familiarity with available tools that have been used and studied in mental health assessment in persons having dementia. Use of rating scales improves differentiation of BPSD. The differentiation of behaviors and their etiology are important to treatment planning. Many of these rating scales are especially useful in institutional settings. In order to improve consistency, all staff using screening tools must be trained in their use and facility inter-rater reliability established.
Table 2.5: Rating scales to assess BPSD

| 1. Comprehensive instruments: Neuropsychiatric inventory (NPI) (Cummings et al., 1994), The Behavior Rating Scale for Dementia of the Consortium to Establish a Registry for Alzheimer's Disease (CERAD-BRSD) (Tariot et al., 1995), and Behavioral Pathology in Alzheimer's disease (BEHAVE-AD) is used to assess the spectrum of BPSD (Reisbert et al., 1987). |
| 2. Depression: Cornell Scale for Depression in Dementia (CSDD) (Alexopoulos et al., 1988). |
| 3. Agitation: Cohen-Mansfield Agitation Inventory (CMAI) (Cohen-Mansfield et al., 1989) and Pittsburg Agitation Scale (PAS) (Rosen et al., 1994) are used to assess agitation. |
| 4. Caregiver distress due to BPSD: Neuropsychiatric inventory—Distress subscale (NPI-D) is used to assess distress that caregivers experience in response to each symptom in NPI (Cummings et al., 1994). |

Sources of information

Rating scales have been based on four sources of information:

- Family caregivers
- Professional caregivers
- Physician’s 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 education level of the caregiver. BEHAVE-AD and 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] (Honigfeld and Klett, 1965), and the 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. Many research studies use the Minimum Data Set (MDS) behavioral symptoms data to assess presence of BPSD. Validity of such data has been called into question recently and in its place, twice-daily completion of a behavioral symptoms checklist containing the MDS items during the week of the assessment has been suggested to significantly improve the accuracy of the recorded data (Bharucha et al., 2008).

**Physicians’ direct observations** of patients have 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 (Sultzer et al., 1992).

**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 (Yesavage et al., 1983).
Content of rating scales for BPSD

BEHAVE-AD 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 degeneration 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, or are state phenomena that are transient and occur more or less randomly in different patients during the course of dementing illness.

References and recommended reading


Books


**Delirium: A differential diagnosis from BPSD**


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


Appendix 2. Rating scales for BPSD in clinical settings


MODULE 3
Etiology

The IPA Complete Guides to Behavioral and Psychological Symptoms of Dementia

BPSD
Specialists Guide

Specialists • Primary Care Physicians • Nurses
### MODULE 3: Etiology

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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 (neurochemical, neuropathology), psychological (e.g., premorbid personality, response to stress), and social aspects (e.g., environmental change and caregiver factors) of etiology.

- There has been much research observing neurochemical and neuropathological changes in the brains of people with dementia, but only broad correlations of changes to BPSD can be made. Further research is required before definite conclusions linking neurochemical and 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. The different changes in neuroimaging and neurochemistry found in various types of dementia suggest that there are different patterns according to the disease type.

- 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 or the development of physical discomforts and disorders.

Introduction

We are in the early 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 or discomfort)
- 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

Studies have indicated different genetic factors to be associated with various BPSD symptoms as well as types of dementia, although some findings are contradictory and others lack independent replication. Most research has focused on Alzheimer’s disease (AD). Many studies have focused on Apolipoprotein E (APOE) genotypes and although there are contradictory findings, the cumulative evidence from longitudinal studies suggests that there is no association between APOE genotypes and BPSD as a whole in AD (Panza et al., 2012).

Alzheimer’s disease

Psychosis. A genome screen for AD involving the combination of samples from the United States and the United Kingdom found that there was a significant association between proband psychosis status and the occurrence of psychosis in AD in siblings with linkage peaks occurring on chromosomes 7 and 15 (Hollingworth et al., 2007). These results suggest an increased familial risk of psychosis in AD. A meta-analysis of serotonergic system genes found that there was a robust, strong, positive association between the C allele of HTR2A and symptoms of psychosis, suggesting that the HTR2A T102C polymorphism is a significant risk factor for psychosis in AD (Ramanathan et al., 2009). These receptors may also modulate antipsychotic response (Engelborghs et al., 2006), and there is an association with psychosis onset and severity of depressive symptoms (Wilkosz et al., 2007). There are contradictory findings about the association of the serotonin transporter gene (SERT) polymorphisms with psychosis (Quaranta et al., 2009; Pritchard et al., 2007; Ueki et al., 2007), although the largest cohort of 1,008 probable AD cases in the UK observed a significant association between SERT polymorphism STin2 and psychosis (Proitsi et al., 2012).

Polymorphisms in dopamine receptors have also been associated with psychosis in most, but not all, studies (Aarsland et al., 2005; Sato et al., 2009), particularly D3 genes, where two studies found homozygous carriers of the 1 allele to be at increased risk (Holmes et al., 2001; Sweet et al., 1998). Some catechol-O-methyltransferase (COMT) haplotypes may increase risk for schizophrenia and other psychoses, including psychosis in AD (Sweet et al., 2005). One group demonstrated a synergic effect of COMT and the serotonin gene-linked promoter region (Borroni et al., 2006). A number of other associations with psychosis have not been independently replicated, including the interleukin-1β gene promoter (the CC genotype and C allele) (Craig et al., 2004a), neuregulin-1 polymorphism (Go et al., 2005), and oligodendrocyte lineage transcription factor 2 gene (Sims et al., 2009).

Aggression and agitation. Aggression in AD has been linked with polymorphic variation at the tryptophan gene (Craig et al., 2004) and polymorphic variation of the serotonin transporter gene (Ueki et al., 2007; Pritchard et al., 2007a). There are contradictory findings about APOE e4 allele and aggression in AD (Craig et al., 2004; Engelborghs et al., 2006; Pritchard et al., 2007b). Agitation in AD has been associated with polymorphisms of the D1 dopamine receptor gene (Holmes et al., 2001) and the dopamine transporter gene 3’ variable number tandem repeats (VNTR) (Proitsi et al., 2012), and there are contradictory findings regarding links with the serotonin transporter gene (Sukonick et al., 2001; Assal et al., 2004). There are also possible associations between variations on the dopamine transporter gene and aberrant motor behavior (Pritchard et al., 2008; Proitsi et al., 2012) and irritability (Pritchard et al., 2008).
**Depression.** Depression in AD is linked to 5-HT2A & 5-HT2C polymorphisms in some (Holmes et al., 2003), but not all, studies (Pritchard et al., 2008b), although the latter study did find a link with anxiety. Depression has also been linked with polymorphisms of the interleukin-1β gene promoter with an association with the T-variant (McCulley et al., 2004), but there is no association with APOE e4 allele (Craig et al., 2005; Pritchard et al., 2007b). More recently a direct association was found between the dopamine receptor 3 Ball polymorphism and depression (Proitsi et al., 2012). There is also some evidence of an association between a positive family history of depression and an increase in the frequency of BPSD occurring for the first time within Alzheimer’s disease (Holmes, 2000).

**Other BPSD.** In their large cohort of 1,008 probable AD cases, Proitsi et al., (2012) found associations between sleep disturbances and the dopamine receptor 4 VNTR and with apathy and the SERT gene VNTR SHTTLPR.

**Other types of dementia**
Few studies have examined genetic influences on BPSD in other types of dementia. In dementia with Lewy bodies (DLB) and Parkinson’s dementia, delusions were associated with the APOE e2 allele (Engelborghs et al., 2006). One study found an association of the APOE e4 allele with aggression in frontotemporal dementia (FTD) but not mixed dementia or AD (Engelborghs et al., 2006).

Further investigations are needed to enhance our knowledge about correlations of genetic abnormalities and specific BPSD symptomatology but the overall picture emphasizes the importance of the serotonergic system (Aarsland et al., 2005).

**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 (AD), dementia with Lewy bodies (DLB), frontotemporal dementia (FTD), or vascular dementia (VaD). Such neurotransmitter changes may have a direct effect on brain function and might also cause neuroendocrine dysfunction in dementia, mainly in the form of overactivity in the hypothalamic-pituitary-adrenal (HPA) axis. Neurotransmitters affected in dementia are the following:

* Acetylcholine
* Dopamine
* Norepinephrine
* Serotonin
* Glutamate
* Gamma-aminobutyric acid

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 Meynart

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 (Pinto et al., 2011). Less well-studied are the effects of cholinergic drugs on BPSD and reduced levels of awareness or alertness. The cholinergic deficit in dementia with Lewy-bodies (DLB) 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 DLB, visual hallucinations and delirium are frequently present throughout the disease course, and in DLB but not AD, there is a reported link between cholinergic deficits in the temporal cortex and visual hallucinations (Minger et al., 2000; Ballard et al., 2000).

In AD there is a reported link between choline acyltransferase (ChAT) activity in the frontal and temporal cortices and aggression and ratios of ChAT activity to dopamine D1 receptor binding, and DA concentration in temporal cortex were also reduced (Minger et al., 2000). There is also a reported link between reduced ChAT activity in the frontal and temporal cortices and aimless and excessive walking in AD (Minger et al., 2000). A review of the cholinergic hypothesis of BPSD concluded that behaviors such as agitation, apathy and psychosis may represent a specific central cholinergic deficiency syndrome (Pinto et al., 2011).

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. As noted earlier, in AD patients with aggression, ratios of ChAT activity to dopamine D1 receptor binding and DA concentration in the temporal cortex are reported to be reduced (Minger et al., 2000). Further, dementia patients with aggression improve in behavior when treated with dopamine-blocking agents (Jeste et al., 2008). Another study reported that apathy in AD was associated with a blunted dopaminergic brain-reward system (Lanctôt et al., 2008). In FTD, the dopamine system has been reported to be associated with aggression and agitation with increased activity and altered serotonergic modulation of dopamine neurotransmission (Engelborghs et al., 2008).
**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. Aggressive behavior in AD has been linked with the combination of locus coeruleus neuronal loss and upregulated expression levels of tyrosine hydroxylase mRNA. This leads to increased postsynaptic sensitivity to norepinephrine, suggesting that a lower concentration of norepinephrine produces an amplified effect possibly due to an increase in norepinephrine synthetic capacity in residual cells (Peskind et al., 1995; Matthews et al., 2002; Herrmann et al., 2004). Upregulation of alpha-1 adrenoreceptors is associated with aggressive behavior and chronic treatment with neuroleptic medication in patients with Alzheimer’s disease (Sharp et al., 2007).

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 compensatory 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 these symptoms (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). There is a complex relationship between aggression in AD and central serotonin activity as measured by prolactin response to fenfluramine challenge with interactions involving gender and cognitive impairment (Lanctôt et al., 2002). Aggressive behavior in AD has been linked with 5-HT1A receptor changes (Lai et al., 2003).

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

Studies involving serotonergic agents for the treatment of BPSD have yielded mixed results (Jeste et al., 2008). One study of 15 patients with frontotemporal dementia and severe BPSD found that a blunted response to a citalopram challenge, implying a dysfunctional serotonergic system, predicted a more positive treatment outcome (Herrmann et al., 2012).
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. There is some limited evidence that memantine, a low-affinity antagonist to glutamate NMDA receptors, might be effective in the treatment of BPSD (Maidment et al., 2008).

Dementia-related changes in the gamma-aminobutyric acid (GABA) system

GABA is a major inhibitory neurotransmitter that has been a target for anxiolytics, anticonvulsants, and hypnotics. Research on the role of disruption of GABA pathways in AD has yielded contradictory findings that might reflect subtypes of the disease (Lanctôt et al., 2004). Changes in GABA may be related to BPSD—for example, plasma GABA levels are correlated with depression and apathy scores on the NPI in severe AD (Lanctôt et al., 2007).

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 subcortical 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 subcortical 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 suppression test in patients with dementia 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.

Some types of aggressive behavior in AD are associated with a blunted growth hormone response to clonidine challenge, a marker of central norepinephrine responsiveness (Herrmann et al., 2004).
Neuropathologic changes in dementia—relationship to BPSD

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

Psychotic symptoms

There is a limited body of literature on the relationship between psychotic symptoms in AD and pathology. In general, psychosis is more common in declining cognition and increasing severity of neuropathology in AD (Aarsland et al., 2005; Savva et al., 2009). A review of the clinicopathological correlates of BPSD concluded that psychotic symptoms in people with dementia usually demonstrate preferential involvement of the frontal lobe and/or limbic regions, although visual hallucinations tend to involve the occipital lobes (Casanova et al., 2011).

Delusions are common in extrapyramidal disorders (Sachdev and Keshaven, 2010). 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. 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 DLB also experience psychotic symptoms, and in such patients, levels of acetyltransferase are reported to be reduced in the parietal, temporal, and occipital cortices. Neuronal counts are decreased in the nucleus basalis (Perry et al., 1990). In DLB, visual hallucinations, but not delusions, are associated with less tangle burden but more cortical Lewy body pathology (Ballard et al., 2004). In DLB, hallucinations and delusions are related to different underlying brain changes with delusions, but not hallucinations, having similar substrates in DLB and AD.

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 (Forstl, 2000) and the anterior cingulate gyrus (Casanova et al., 2011). More severe neuropathologic changes in the aminergic brain stem nuclei and loss of dorsal raphe serotonergic nuclei are associated with depressive symptoms in AD patients (Forstl et al., 1992).

Structural neuroimaging

There is limited evidence from structural neuroimaging studies for relationships between ventricular size (or atrophy) and clinical symptoms, including:

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

More recent structural imaging studies have focused on FTD. There have been inconsistent findings regarding specific abnormalities associated with apathy in FTD but in general there is disruption of cortical-basal ganglia circuits. One study found that apathy was associated with atrophy in the dorsal anterior cingulate cortex and dorsolateral prefrontal cortex (Massimo et al., 2009); a second study reported that severity of apathy correlated with atrophy in the right dorsolateral prefrontal cortex (Zamboni et al., 2008); while a third study of behavioral variant FTD found apathy to be associated with atrophy of the right caudate (including the ventral striatum), the right temporoparietal junction, right posterior inferior and middle temporal gyri, and left frontal operculum-anterior insula region (Eslinger et al., 2012). Disinhibition in FTD was associated with atrophy in the medial orbital frontal cortex in one study (Massimo et al., 2009), while severity of disinhibition correlated with atrophy in the nucleus accumbens, right superior temporal sulcus, and right mediotemporal limbic structures in another study (Zamboni et al., 2008). A third study reported atrophy in orbitofrontal/subgenual, medial prefrontal cortex and anterior temporal lobe areas (Hornberger et al., 2011). A recent meta-analysis concluded that there was evidence of gray matter changes in the frontal-striatal-limbic brain areas in patients with behavioral variant FTD (Pan et al., 2012).

### Functional neuroimaging

In recent years there has been a marked increase in functional imaging studies of BPSD, particularly in AD, and these studies suggest that BPSD (in AD at least) are associated with dysfunction in specific brain regions. Table 3.1 summarizes some of the functional neuroimaging findings in AD.

**Table 3.1: Functional neuroimaging and BPSD in Alzheimer’s disease**

<table>
<thead>
<tr>
<th>BPSD</th>
<th>Neuroimaging finding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychosis</td>
<td>Hypoperfusion in frontal and temporal lobes (Robert et al., 2005)</td>
</tr>
<tr>
<td>Depression</td>
<td>Hypoperfusion in frontal, temporal, and parietal lobes (Robert et al., 2005)</td>
</tr>
<tr>
<td>Aggression</td>
<td>Hypoperfusion in temporal cortex (Hirono et al., 2000; Lanctôt et al., 2004)</td>
</tr>
<tr>
<td>Apathy</td>
<td>Hypoperfusion in frontosubcortical structures, especially anterior cingulate (Migneco et al., 2001; Benoit et al., 2002; Lanctôt et al., 2007; Marshall et al., 2007)</td>
</tr>
<tr>
<td>Sleep loss</td>
<td>Hyperperfusion in right middle frontal gyrus (Ismail et al., 2009)</td>
</tr>
<tr>
<td>Appetite loss</td>
<td>Hyperperfusion in left ant. cingulate and left orbitofrontal cortices (Ismail et al., 2008)</td>
</tr>
</tbody>
</table>

In DLB, hypometabolism in visual association areas rather than the primary visual cortex are reported to be involved in visual hallucinations (Pernecky et al., 2008). In a study of the behavioral variant of FTD, the “disinhibited” phenotype correlated with SPECT scan hypoperfusion in the region of the anterior cingulate and anterior temporal cortex bilaterally, and for apathetic phenotype, in the left dorsolateral frontal cortex (Borroni et al., 2012).
Circadian rhythms—relationship to BPSD

Changes in circadian rhythm (e.g., fragmented sleep-wake patterns) may be age-related and occur in many older persons, but these changes are particularly pronounced in patients with AD, DLB, and other synucleinopathies. Changes in sleep architecture (i.e., reduced rapid eye movement and slow-wave sleep) mean that 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), but a minority of dementia patients show a clear increase of agitation in the later hours peaking at around 4:00 p.m. (Cohen-Mansfield, 2007). Cohen-Mansfield hypothesized that day-shift staff fatigue might be a contributing explanation for the phenomena.

Investigations have shown that Alzheimer’s patients reveal increased nocturnal activity and a significant phase-delay in their rhythms of core-body temperature and of activity compared with patients with FTD. The rhythms of FTD patients are highly fragmented and phase-advanced in comparison with controls, and they are apparently uncoupled from the rhythm of core-body temperature (Harper et al., 2001). Differences have also been reported between AD and DLB in the type of sleep/wake cycle disturbances (Robert et al., 2005).

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.

Other clinical contributors to BPSD

In general, BPSD increase with declining cognition (Cohen-Mansfield and Libin, 2005; Starr and Lonie, 2007; Pagonabarraga et al., 2008; Proitsi et al., 2009), although there is some evidence that premorbid intelligence might be a factor (Starr and Lonie, 2007). BPSD are also associated with
increasing functional disability (Hinton et al., 2008), and impaired communication is associated with aggression and depression (Talerico et al., 2002). There are gender differences with psychosis (Steinberg et al., 2006; Proitsi et al., 2009; Murayama et al., 2009; Kitamura et al., 2012), verbal agitation (Draper et al., 2000; Cohen-Mansfield and Libin, 2005), anxiety (Steinberg et al., 2006; Kitamura et al., 2012) being more common in females, and aggression more common in males (Whall et al., 2008; Lovheim et al., 2009; Kitamura et al., 2012). Anxiety and depression are more common in younger individuals (Savva et al., 2009; Proitsi et al., 2009) and irritability in higher-functioning groups (Savva et al., 2009).

Executive impairment early in the course of dementia was found to be associated with BPSD and carer stress 3-6 years later (Tsoi et al., 2008). Frontal symptoms are associated with increased severity and frequency of agitation and aggression, as well as increased severity of psychosis and depression (Senanarong et al., 2004; Engelborghs et al., 2006).

Some BPSD are more common in different types of dementia, although there are contradictory findings. Disinhibition, apathy, and aberrant motor behavior distinguish FTD from other types of dementia in most, but not all, studies (Senanarong et al., 2004; Engelborghs et al., 2005; Srikanth et al., 2005; De Vugt et al., 2006), while high rates of hallucinations and disinhibition have been reported in DLB (Engelborghs et al., 2005; Chiu et al., 2006). There have been few differences in BPSD or discrepant findings reported between VaD and AD (Senanarong et al., 2004; Srikanth et al., 2005; Steinberg et al., 2006; de Vugt et al., 2006) and between FTD and progressive supranuclear palsy (Yatabe et al., 2011).

**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. 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. Patients who have shown suspicious, aggressive, or controlling behaviors prior to the onset of dementia are more likely to subsequently develop BPSD.

A high level of neuroticism in Alzheimer’s patients might be associated with a higher risk of BPSD. A low level of premorbid neuroticism was linked to depressive signs and symptoms, and troublesome behavior was associated with a higher level of premorbid neuroticism in one study (Meins et al., 1998), while another found that delusions of theft were related to premorbid neurotic personality (Murayama et al., 2009). A third study found a relationship between neuroticism and anxiety/total NPI score and not affective disturbance (Archer et al., 2007). This latter study also found that lower premorbid agreeableness was associated with agitation and irritability symptoms in Alzheimer’s disease and predicted an “agitation/apathy” syndrome. A study of wandering behavior reported an association with premorbid extroversion and negative verbalization stress response (Song and Algase, 2008). However, results are mixed about whether an individual’s premorbid personality has a role in the development of BPSD—for example, one group found no meaningful relationship between premorbid personality and subsequent BPSD, and concluded that biological and environmental factors appear more important (Low et al., 2002).
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 overstimulation.

Most patients with dementia 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 (Steinberg et al., 2006). They may trigger these symptoms, and this may include through the development of comorbid delirium (Holtta et al., 2011), or they may contribute to their presence over time. One study found that 36% of community residing people with dementia and behavioral symptoms had undiagnosed acute illnesses with bacteriuria (15%), hyperglycemia (6%) and anemia (5%) being most prevalent. The behavior most often associated with detected illness was resisting or refusing care (Hodgson et al., 2011). The following disturbances play a major role: cardiovascular disease, urinary tract and other infections, and pain syndromes or somatic symptoms due to pharmacologically mediated adverse events. Discomforts have been found to be associated with verbal agitation and non-aggressive physical agitation (Pelletier and Landreville, 2007). Such discomforts might also relate to the physical environment such as high climate temperature (Cornali et al., 2004).

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

**Environmental, physical, and social contributors to BPSD**

There is evidence that certain environmental features in residential care are associated with lower levels of BPSD and better well-being of residents (Fleming et al., 2009). In their review of the empirical literature on the design of physical environments for people with dementia, Fleming et al., (2009) found:

- Unobtrusive safety features improve resident well-being and reduce depression, though there is some evidence that an overemphasis on safety might have a detrimental effect. One study reported that increased security measures were associated with risk-taking behavior and passive self-harm (Low et al., 2004).
- Provision of a variety of spaces in environments reduces anxiety and depression, improves social interaction, and might assist residents in finding their way around.
- Availability of single rooms is beneficial.
- Optimization of levels of stimulation by reducing unhelpful stimulation while increasing helpful stimuli is effective—for example, there is good evidence that illumination beyond that which is considered to be normal can improve sleep patterns and reduce BPSD.
- Small facility size is associated with lower levels of aggression.
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, mortality and agitation in patients with dementia, with many patients showing significant disturbed behavior and disorientation for three months after a move (Anthony et al., 1987). The greatest effects of relocation on mortality are observed among patients with moderate cognitive impairment.

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. Caregiver avoidance and care-receiver insecure attachment styles are associated with increased BPSD (Perren et al., 2007). 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. Inappropriate caregiver strategies have been reported to be associated with delusions (Riello et al., 2002), aggression (Hamel et al., 1990), and hyperactive behavior (de Vugt et al., 2004).

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 to 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) about the likely diverse reactions of different individuals to such simple interventions as touch (see Module 5).

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 dementing 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. Biological and non-biological 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.

References and recommended reading

Genetic abnormalities in demented patients—relationship to BPSD


**Neurotransmitter changes in dementia—relationship to BPSD**


**Neuropathology changes in dementia—relationship to BPSD**


**Neuroimaging (structural and functional)**


**Circadian Rhythms—relationship to BPSD**


**Other clinical contributors to BPSD**


The IPA Complete Guides to BPSD – Specialists Guide  
Module 3: Etiology


**Personal/psychological contributors to BPSD**


**Environmental, physical, and social contributors to BPSD**


MODULE 4
Role of family caregivers
The IPA Complete Guides to Behavioral and Psychological Symptoms of Dementia
MODULE 4: Role of family 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 caregiver and the person with dementia significantly determines whether family care can be maintained.
- An effective care system enables caregivers to continue caring for their family members with dementia 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 to interact with the person with dementia may prolong the caregiver’s ability to provide in-home care and improve the quality of life of both.
- Behavioral and psychological symptoms of dementia (BPSD) are a potent cause of caregiver distress. Less well appreciated is that caregiver distress and poor interpersonal relations between the person with dementia 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 the person with dementia are more likely to misinterpret agitated behavior as purposefully provocative and worsen the situation with an angry retort.
- Caregiver interventions have proved to be effective in increasing caregiver knowledge and reducing caregiver distress and BPSD.

Introduction

Support by caring relatives is the key to continuing community care of people with dementia. Community care recognizes the right of people with dementia to live as independently as possible in familiar surroundings, such as at home. Family care may not be possible or sustainable for a number of reasons. Many factors 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 BPSD, and the burden that they create for the family caregiver, are key factors in precipitating a move from family care to nursing home or other residential care (Merritt, 2011; Moore et al., 2013; Nobili et al., 2004; Yaffe et al., 2002).

Strategies have been demonstrated clinically and empirically to reduce the burden that caregivers experience in looking after a person with dementia. This module reviews the impact of BPSD on the psychological and physical health of family caregivers (i.e., their contribution to caregiver burden) as well as interventions to reduce that burden related to BPSD.
What is caregiver burden?

Schulz and Martire (2004) describe caregiving as:

“...the provision of extraordinary care, exceeding the bounds of what is normative or usual in family relationships. Caregiving typically involves a significant expenditure of time, energy, and money over potentially long periods of time; it involves tasks that may be unpleasant and uncomfortable and are psychologically stressful and physically exhausting.”

Three different types of burden have been associated with a caregiving role (Montgomery et al., 1985; Savundranayagam et al., 2011; Savundranayagam and Montgomery, 2010):

- **Objective burden** refers to the perceived disruption to tangible aspects of a caregiver’s life such as personal privacy and time for recreational activities.
- **Subjective demand burden** refers to the extent that the caregiver perceives their care responsibilities to be overly demanding. This includes reports of unreasonable requests and demands made by the care recipient.
- **Subjective stress burden** is the emotional impact of their role on the caregiver such as relationship stress, tension, anxiety, and depression.

Emotional, physical, and social burden as well as depression and psychological comorbidity have also been reported in caregivers of those with mild cognitive impairment (MCI; Bruce et al., 2008; Kim and Choi, 2012; Okura and Langa, 2011; Seeher, Brodaty et al., 2012; Seeher, Low et al., 2012) with greater burden being associated with neuropsychiatric symptoms (Ryan et al., 2012; Van Der Mussele et al., 2011; Werner, 2012).

Measuring caregiver burden

Although a recognized gold standard for measuring caregiver burden is lacking (Levy et al., 2012), the most widely referenced scale is the Zarit Caregiver Burden Interview (ZBI; Bachner and O’Rourke, 2007; Prince et al., 2012; Van Durme et al., 2012; Zarit et al., 1980). The instrument encompasses 22 items relevant to the wide range of interacting issues that can impact on caregiver burden and provides a global rating of burden. Higher scores indicate greater distress. Several short (Bedard et al., 2001; Gort et al., 2010; O’Rourke and Tuokko, 2003a, 2003b) and non-English language versions of the ZBI have been developed (Arai et al., 2003; Braun et al., 2010; Hirono et al., 1998; Van Durme et al., 2012).

Other measures of caregiver burden include:

- Caregiver Burden Inventory (Novak and Guest, 1989)
- Caregiver Perceived Burden Questionnaire (Erd er et al., 2012)
- Caregiver Strain Index (Robinson, 1983; Sullivan, 2002; Thornton and Travis, 2003)
- Montgomery Borgatta Caregiver Burden Scale (Montgomery et al., 1985)
- Neuropsychiatric Inventory Caregiver Distress scale (Cummings, 1997; Cummings et al., 1994; Fuh et al., 2006; Kaufer et al., 1998)
- Neuropsychiatric Inventory—Nursing Home Distress Scale (Boada et al., 2005; Wood et al., 1999; Wood et al., 2000)
- Neuropsychiatric Inventory Questionnaire Caregiver Distress Scale (Kaufer et al., 2000)
- Relatives’ Stress Scale (Greene et al., 1982; Ulstein, Wyller et al., 2007)
Factors associated with caregiver burden

BPSD, rather than cognitive dysfunction per se or physical dependence/functional impairment, impose the greatest burden on caregivers (Gitlin, 2012a; Levy et al., 2012; Machnicki et al., 2009; Pinquart and Sörensen, 2003; Savundranayagam et al., 2011; Savundranayagam and Montgomery, 2010).

BPSD include:

- Aggression
- Disinhibited behaviors
- Agitation
- Nocturnal disruption
- Anxiety
- Psychotic symptoms
- Apathy
- Vocally disruptive behaviors
- Depression
- Wandering

The above symptoms are recognized as the most burdensome and the most common reasons for psychiatric referral and premature institutionalization (Desai et al., 2012). However, the degree of burden associated with individual BPSD varies (Allegri et al., 2006; Barth et al., 2011; Bowen et al., 2012; Garavello et al., 2010; Lee and Thomas, 2011; Matsumoto et al., 2007; Okura and Langa, 2011; Ornstein and Gaugler, 2012; Ornstein, 2012; Rocca et al., 2010; Zweig et al., 2012).

While 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. Caregiver characteristics that are either predictive of, or alleviate, burden are shown in the boxes below and Figure 1 (Bakker et al., 2010; Brodaty and Green, 2002; Brodaty and Hadzi-Pavlovic, 1990; Chemali et al., 2012; Cohen, 2004; Contador et al., 2012; Cooper et al., 2007; Cooper et al., 2006; Cooper et al., 2008; Etters et al., 2008; Fearon et al., 1998; Gallagher et al., 2011; García-Alberca et al., 2012a; 2012b; Gilleen et al., 2012; Gronning et al., 2012; Kunik et al., 2010; Livingston et al., 2005; Melo et al., 2011; Papastavrou et al., 2011; Pekkarinen et al., 2004; Prince et al., 2012; Romero-Moreno et al., 2011; Savundranayagam et al., 2005; Savundranayagam and Montgomery, 2010; Silvestre and Guarda, 2011; Vitaliano et al., 1991; Zarit et al., 2010; Zawadzki et al., 2011; Zucchella et al., 2012).
### Table 4.1: Predictors of burden

#### Predictors of burden: Characteristics of the person with dementia

**Very important in predicting caregiver burden**
- Delusions, hallucinations and depression
- Disruptive behaviors (e.g., physical aggression, calling out, disinhibition)

**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 person with dementia
- Communication problems

**Doubtful or not important in predicting caregiver burden (when above variables are controlled for)**
- Type of dementia, particularly those with greater frontal involvement
- Severity of dementia (i.e., level of cognitive impairment, need for supervision and assistance)
- Cognitive status
- Functional status (i.e., 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
- Older > younger
- Propinquity (caregivers in closest contact; cohabiting caregivers are under most stress)
- Immature coping mechanisms
- Less support from family and friends
- Less knowledge of dementia, its effects and management
- Poor premorbid relationship with person with dementia
- High levels of negative attitude and negative expressed emotions, notably hostility and criticism
- Personality influences
- Spouse versus caregiver role discrepancies

#### 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)
- Care providers belief in their personal abilities and internal locus of control
## Cultural, racial and/or ethnic factors

Cultural, racial and/or ethnic differences can mediate factors associated with caregiver burden (Zekry et al., 2012) and contribute to BPSD (see Module 7). The following are relevant to specific countries and/or cultural groups:

### Table 4.2: Cultural, racial and/or ethnic differences

<table>
<thead>
<tr>
<th>Authors</th>
<th>Country/cultural group</th>
<th>Subject area</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abdollahpour et al., (2011)</td>
<td>Iran</td>
<td>Characteristics of person with dementia and caregiver burden</td>
</tr>
<tr>
<td>Akpinar et al. (2011)</td>
<td>Turkey</td>
<td>Gender effects on caregiving</td>
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<td>Bergvall et al. (2011)</td>
<td>Sweden, UK, USA</td>
<td>Predictors of perceived caregiver burden</td>
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<td>Cheah et al. (2012)</td>
<td>Multiethnic Asian in Singapore</td>
<td>Caregiver characteristics</td>
</tr>
<tr>
<td>Cipriani et al. (2011)</td>
<td>Japan</td>
<td>Aggressive behavior and caregiver stress</td>
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**Exacerbating factors**
- Social isolation
- Lack of knowledge
- Poor skills
- Immature coping
- Guilt
- Poor marital relationship
- High expressed emotion

**Dementia**

**Dependency and problem behaviors**

**Burden on caregiver**

**Caregiver strain**
- Psychological
- Physical
- Financial
- Social

**Protective factors**
- Practical support
- Family help
- Problem focused coping

**Figure 4.1: Model of effects of dementia on caregivers.** Reprinted with permission from Brodaty (1997) and based on Poulshock and Deimling (1984).
The impact of BPSD on family caregivers

Psychological health

BPSD are the most consistent and important predictors of psychological distress in family caregivers, accounting for approximately 25% of the variance in psychological morbidity (Ballard et al., 2000; Black and Almeida, 2004; Brodaty, 1997). This relationship has been shown in studies from England, Scotland, Wales, Australia, Germany, Sweden, South America and the United States. It also has been shown for caregivers of people with Alzheimer’s disease, vascular dementia, Huntington’s chorea, Parkinson’s disease, and stroke. The relationship holds whether psychological morbidity or stress is used to measure the effects on caregivers.

Caregivers are at high risk for developing psychological distress (Garcia-Alberca et al., 2012a; 2012b; 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 those with dementia has ranged from 23–85% in developed countries (Adkins, 1999; Clare et al., 2002; Cuijpers, 2005) and rates of anxiety between 16–45% (Cooper et al., 2006; 2007; Schulz et al., 1995). Suicidal thoughts in caregivers have been associated with poorer mental health, lower community service use and dysfunctional coping strategies (O’Dwyer et al., 2013). In developing countries, rates of psychiatric morbidity range from 40–75% (The 10/66 Dementia Research Group, 2004). Furthermore, 7–31% of dementia caregivers take psychotropic drugs, which are slightly, but significantly, higher rates than expected in the general population (Camargos et al., 2012; Clipp and George, 1990; Schulz et al., 1995; Sleath et al., 2005).

Anger and resentment are emotions commonly felt by caregivers, sometimes bringing the caregiver to the point of violence (Cooper et al., 2008; Croog et al., 2006). Characteristics associated with caregivers being physically and psychologically abusive are more time spent caring, more aggressive behavior from care recipients, higher caregiver burden, poorer spousal relationship, and greater caregiver cognitive impairment, anxiety, depression and/or physical symptoms (Beach et al., 2005; Cooper et al., 2010). Specific BPSD such as aggression, nocturnal disruption and emotional lability are commonly identified determinants of caregivers’ abusive behavior (Cooney et al., 2006; Cooper et al., 2010; Croog et al., 2006; Hansberry et al., 2005; Kim et al., 2012; Yan and Kwok, 2011).

Levels of interpersonal and family stress are high in families caring for a person with dementia. Among variables most strongly associated with caregivers’ perceptions of interpersonal and family stress are behavioral and emotional changes experienced by the person with dementia, changes in the person with dementia’s sleep pattern (Schulz et al., 1995) and demanding behaviors (Arango-Lasprilla et al., 2009; Brodaty and Hadzi-Pavlovic, 1990; Kramer et al., 1993; Peisah, 2006). Aneshensel and colleagues (1995) examined caregivers’ responses as BPSD increase or decrease over time. BPSD were associated with greater caregiver depression when they resulted in an increase in subjective burden and a feeling of being trapped in the caregiving role.

Physical health

Caregiving can impact on physical health (Hooker et al., 2002; Vitaliano, 2003) through compromised immune function (Schulz and Martire, 2004; Segerstrom et al., 2008; Vedhara et al., 1999) and greater prevalence of heart disease among men caring for a spouse with
Alzheimer’s disease (Vitaliano et al., 2002). Evidence also links caregiving to detrimental health-related behaviors when caregivers are less likely to engage in preventative health behaviors such as exercise, and more likely to smoke, drink alcohol and/or experience poor sleep patterns (Schulz and Williamson, 1997).

An important area of research evaluating health outcomes in caregivers focuses on changes in subclinical disease as indicators of health effects (Vitaliano et al., 2003):

- Hypertension
- Changes in stress hormones and neurotransmitters
- Antibody levels
- 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 stress and 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. Caring for a person with dementia can reduce the caregiver’s life expectancy. Compared to non-caregivers, caregivers who report strain and burden associated with caregiving have had an increased rate of mortality (Schulz and Beach, 1999).

The impact of family caregivers on BPSD

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. Documented significant correlations between caregiver distress and BPSD levels in people with dementia typically do not include the direction of causality (Cerveira et al., 2011; Dunkin and Anderson-Hanley, 1998; Fischer et al., 2012; Guerrero, 2012; Holst and Edberg, 2011; Kunik et al., 2010; Leggett et al., 2011; Mohamed et al., 2010; Ng et al., 2012; Okura and Langa, 2011; Tschanz et al., 2012; Van Der Linde et al., 2012). It is generally assumed that BPSD cause caregiver distress but the reverse may also be true (Kunik et al., 2010) (see Module 3).

The caregiver’s approach to the person with BPSD can have a direct and significant impact on the person with dementia (see Table 4.3 below). For example, caregivers may believe that the BPSD are under the person with dementia’s control and so represent antagonistic feelings toward the caregiver. Caregivers may experience the person with dementia’s forgetfulness as irresponsibility, irascibility as a lack of appreciation, and repetitive questioning as a deliberate attempt to annoy. Caregivers may then express criticism or hostility toward the person with dementia, which can increase distress and exacerbate the behavior. Caregiver fatigue can likewise contribute to BPSD (Khachiyants et al., 2011) and higher caregiver burden. Caregiver depression has also been associated with reduced quality of life in the person with dementia (Black et al., 2012; Mohamed et al., 2010; Mougias et al., 2011).
Table 4.3: Caregiver behaviors that can exacerbate BPSD

- Creating sudden and unexpected changes in a person with dementia’s routine or environment
- Instigating “power struggles” with the person with dementia: for example, insisting that the person with dementia do something a certain way or wear a particular article of clothing
- Placing demands on the person with dementia that exceed his or her capabilities
- Being excessively critical of the person with dementia
- Ignoring the person with dementia’s needs
- Being excessively rigid or controlling
- Repeatedly prompting or questioning in an attempt to induce the person with dementia to remember something
- Expressing anger or aggression toward the person with dementia
- Becoming exasperated
- “Talking down” to the person with dementia as if to a child

Adverse caregiver behaviors have the potential to incite a catastrophic reaction when the person with dementia exhibiting the behavior is unable to deal with the additional stress.

Caregiver interventions for BPSD

A range of caregiver interventions can relieve caregiver burden, decrease caregiver psychological morbidity and delay institutionalization (Brodaty et al., 2003; Pinquart and Sörensen, 2006). An additional benefit is that these caregiver interventions, though not specifically focusing on BPSD, can decrease caregivers’ appraisal and negative reactions to BPSD which may contribute to reducing BPSD in care recipients (Ayalon et al., 2006; Farran et al., 2007; Gallagher-Thompson et al., 2007; Glueckauf et al., 2003; Hebert et al., 2003; Hepburn et al., 2005; Mahoney et al., 2003; Marriott et al., 2000; Mittelman et al., 2006; Teri et al., 2002). Caregiver skills training or education interventions can include systematic, structured and individualized approaches (Gitlin et al., 2010b; Teri et al., 2005), as well as caregiver programs which target coping strategies, knowledge of dementia and/or BPSD management (Bourgeois et al., 2002; Brodaty and Gresham, 1989; Gavrilova et al., 2009; Guerra et al., 2011; Liddle et al., 2012; Monti et al., 2012; Teri et al., 2003; Teri et al., 1997; Ulstein, Sandvik et al., 2007). Caregiver training has also been compared with drug treatments (Teri et al., 2000).

Multicomponent interventions have also been shown to be of benefit. These include programs which may provide a combination of information, role playing, problem solving, BPSD skills training, stress management, telephone support, multidisciplinary collaboration, care management, cognitive rehabilitation, counseling, motor stimulation and/or light therapy (Belle et al., 2006; Brodaty et al., 2003; Burgio et al., 2009; Burns et al., 2003; Callahan et al., 2006; Dias et al., 2008; Gitlin et al., 2008; 2003; 2010a; Johnson et al., 2013; McCurry et al., 2005; Mittelman et al., 2004; Moniz-Cook et al., 2008; Nobili et al., 2004; Senanarong et al., 2004).
Enhancing the skills of the caregiver to interact with the person with dementia and better manage BPSD may prolong the caregiver’s ability to provide in-home care and enhance the quality of life of both parties. In a meta-analysis of 23 studies meeting criteria for level II or III-1 evidence (NHMRC, 2000, 2009) Brodaty and Arasaratnam (2012) found that nonpharmacological interventions delivered by family caregivers have the potential to reduce the frequency and severity of BPSD, with effect sizes at least equaling those of pharmacotherapy, as well as to reduce caregivers’ adverse reactions. Successful interventions typically provided nine to 12 individual sessions in the home of the person with dementia and the caregiver, tailored to their specific needs using multiple components over 3–6 months with periodic follow-up.

Individualized, multidimensional, flexible caregiver interventions that involve follow-up and an ongoing relationship between helper and caregiver demonstrate positive outcomes for caregivers as well as BPSD in care recipients (Lavoie et al., 2005) and can delay nursing home placement (Brodaty et al., 2003). Caregiver education or support in isolation appear to be less beneficial (Brodaty, 1994; Brodaty et al., 1994; Charlesworth et al., 2008; Devor et al., 2008; Gormley et al., 2001; Kurz et al., 2009; Marriott et al., 2000).

Those with dementia in the developing world rely primarily on families for support as health services are often ill-equipped to meet their needs (Dias et al., 2008; Prince et al., 2004; Shahly et al., 2013). Family caregivers with limited resources face additional challenges in developing countries as awareness and understanding of dementia are lacking; symptoms may be perceived to be part of normal aging, or denied because of the stigma attached to the illness (Dias et al., 2008; Patel and Prince, 2001; Senanarong et al., 2004). Caregiver interventions may be of benefit in developing countries where availability of formal supports is limited (Dias et al., 2008; Gavrilova et al., 2009; Guerra et al., 2011; Prince et al., 2012; Senanarong et al., 2004). Their impact may be greater in these settings than in high income countries (Brodaty et al., 2003; Gavrilova et al., 2009; Wortmann, 2011).

Reducing BPSD can improve caregiver well-being and conversely the relief of caregiver burden can considerably decrease BPSD.

Other interventions

Research to assess the feasibility and/or acceptability of utilizing assistive technology in the management of BPSD is limited (Daniel et al., 2009; Westphal et al., 2010). Examples include telecare monitoring (Dunk and Doughty, 2006), automated telephone caregiver support (Mahoney et al., 2003), a computer-telephone integrated support system (Eisdorfer et al., 2003) and internet-based caregiver education (Lewis et al., 2010). The Aladdin Project is a pilot study of a technology platform installed in the home that detects BPSD and caregiver burden (Haritou et al., 2011; Haritou et al., 2012; Saez et al., 2011; Saeza et al., 2012). The system integrates monitoring safety and health aspects of the person with dementia with the workload, quality of life and mental health of the caregiver (Cuno et al., 2011; Haritou et al., 2012). Assistive technologies may help to delay institutionalization however, they typically require significant caregiver input and caregivers’ lack of awareness of the technology may be a barrier to their use (Daniel et al., 2009; Van Den Heuvel et al., 2012).
Alzheimer Associations are another important form of intervention. Alzheimer’s Disease International (ADI) is a global umbrella organization with associations in more than 80 countries of the developed and developing world (http://www.alz.co.uk/). Alzheimer’s Associations are non-profit organizations which support those with dementia and their caregivers. Many of the associations provide Help Notes to assist in the management of BPSD, for example:


Referral of people with dementia and their families to Alzheimer Associations is part of the clinician’s therapeutic collection of resources. Respite care and community services also offer support to caregivers. The effects of Alzheimer’s Associations or respite care on BPSD or caregivers’ reactions have not been adequately assessed.

Pharmacological interventions targeting BPSD have proven advantageous in reducing caregiver burden. A systematic review of eight randomized placebo-controlled double-blind studies of psychotropic medication for BPSD found that drugs targeting behavioral disturbances in the person with dementia reduced caregiver burden as well as time spent in caregiving and supervision (Schoenmakers et al., 2009).

**Barriers to caregivers seeking assistance**

Access to interventions aimed at reducing BPSD and caregiver burden may be limited by many factors, both logistical and perceived. These can include transportation costs, loss of wages, community privacy issues, stigma associated with dementia, mistrust of “outsiders” (Daunt, 2003; Glueckauf et al., 2005), distance, lack of awareness of available resources (Brodaty et al., 2005; Lim et al., 2012; Moore et al., 2013), reluctance to define themselves as caregivers (Liu 2009), financial strain (Gitlin, 2012b), lack of respite for the person with dementia to enable attendance (Winterton and Warburton, 2011), lack of cultural, social and/or religious concordance (Glueckauf et al., 2012; Napoles et al., 2010) and perceived lack of need (Brodaty et al., 2005; Lim et al., 2012). Creative solutions, flexibility and additional resources may be necessary to help overcome such barriers (Brodaty et al., 2005; Burgio et al., 2009; Glueckauf et al., 2012; 2005; Hepburn et al., 2003; Winterton and Warburton, 2011).

**Elements of success**

Interventions targeting caregiver burden and BPSD are most successful when they:

- Focus on the person with dementia as well as the caregiver
- Focus on training and skill building in addition to education and support; e.g., role plays, use of video feedback
- Are multidimensional, flexible and tailored to the needs of the caregiver and care recipient
- Are of sufficient duration and intensity and followed up with booster sessions
- When possible, are delivered to individual dyads or families in their own homes
There is also some evidence that the following are important:

- Combining pharmacotherapy where indicated (see Module 6)
- Including provision of information to family caregivers, which is insufficient alone unless combined with:
  - Techniques for dealing with specific BPSD (see Module 5)
  - Techniques for ensuring the person with dementia’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)
- Collaborative care with a professional care manager; e.g., nurse working with caregiver
- Focusing on the medium to long-term

### Recommendations for caregivers

**Table 4.4: Caregiver characteristics that alleviate the occurrence and impact of BPSD**

- An empathic, patient, kind, caring, warm attitude toward the person with dementia
- Efforts to understand the cause(s) of and meaning behind the behavior
- Flexible personality, enabling the caregiver to avoid rigid insistence on compliance
- Adaptability and ability to accept change
- Maintenance of realistic expectations of the person with dementia’s abilities
- Reasonable degree of tolerance for “problem” behaviors such as repetitive actions
- Commitment to keep the person with dementia involved in day-to-day activities
- Fostering a sense of individualism and usefulness in the person with dementia
- Allowing the person with dementia to maintain a perception of control over his or her life and environment
- Sense of genuine concern for the person with dementia’s well-being and best interests
- Respect for the person with dementia as an individual with valid 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 which dwell on the person with dementia’s limitations
- Development and maintenance of an emotional support structure
Conclusion

Family 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 people 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; i.e., for the person behind the behavior, and the world of the person with dementia.

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MODULE 5
Non-pharmacological treatments

The IPA Complete Guides to Behavioral and Psychological Symptoms of Dementia

Specialists Guide
# MODULE 5: Non-pharmacological treatments

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Key messages

- There is now a substantial body of evidence supporting the use of non-pharmacological treatments of the behavioral and psychological symptoms of dementia (BPSD).

- Even when BPSD are caused by physical discomfort, major depression or psychosis, psychosocial interventions will prove helpful when offered in combination with analgesic, antidepressant or antipsychotic medications.

- Psychosocial approaches are indicated as first-line approaches to all emotional and behavioral disturbances in people with dementia.

- All of the psychosocial interventions described here work best when they are tailored to people’s backgrounds, interests and capacity.

- Family and professional caregivers are key collaborators. It is important to provide them with necessary information and education and to support them as they test and refine their responses to challenging symptoms.

- The physical environment can help prevent or minimize BPSD by reducing distress, encouraging meaningful activity, maximizing independence and promoting safety.

Introduction

In Western countries, many people with serious, persistent BPSD live in nursing homes. Much of the information in this module is directed to medical, nursing and allied health clinicians who work in that setting but the principles expressed here apply equally well to the family carers of people with dementia who live in their own homes.

This module examines:
- Psychosocial models of BPSD
- Principles of dementia care
- Assessment methods
- Specific treatments
- Physical environment

Additional information on responses to BPSD can be found on the web sites listed at the end of this module.

Understanding BPSD

While changes in brain structure and function certainly contribute to BPSD (See Module 3), psychological processes also play a part. People with dementia may feel great distress as a result of their condition and the responses of those around them are critical. Caregivers typically seek to provide what support is required in a calm, affirming and respectful manner. Sometimes, though, they respond inadvertently in ways that make distress worse. Three different models have been put forward to explain how this works:
• **Learning theory** states that behaviors are reinforced if they lead to people being given more attention. Yelling, for example, will increase in frequency if staff members attend to residents when they are noisy and ignore them when they are quiet (Teri et al., 1998). Paying more attention to people when they are quiet should therefore lead to a reduction in yelling.

• According to the **unmet needs theory**, so-called challenging behaviors stem from normal human needs for meaningful activity, emotional validation and social interaction (Cohen-Mansfield, 2001). Since people with advanced dementia cannot always voice these needs, or take action to address them, their carers must take the initiative. A need for physical movement and social engagement, for example, might be addressed by a carefully tailored exercise program.

• According to the **stress threshold model**, dementia reduces people’s capacity to cope with stress, resulting in inappropriate behaviors when levels of stress are excessive (Hall and Buckwalter, 1987). Stress can be reduced to tolerable levels by attending to signs of tension and providing opportunities for relaxation.

In reality, most psychosocial treatments blend elements of all three models. For example, a music therapy session in a nursing home might lead to a reduction in BPSD by:

• Generating positive attention from staff members and co-residents while participating in the group, thereby reinforcing normal social behavior
• Meeting a resident’s need for creative, enjoyable activity
• Providing an optimal level of stimulation

Other factors that increase stress and might therefore worsen BPSD, include:

• Poor vision or hearing
• Limited mobility
• Pain or physical discomfort
• Incontinence
• Lack of fluency in the local language

**Underlying principles**

Since BPSD are triggered in part by psychological forces, it follows that family and professional caregivers can interact with people with dementia in ways that prevent symptoms emerging, or at least reduce their frequency and severity. Based on the models described above, caregivers should aim to:

• Encourage socially appropriate behaviors
• Create opportunities for social interaction and meaningful activity
• Ensure that levels of stimulation are neither too high nor too low

To help reduce the impact of sensory handicap, functional incapacity and cultural isolation, caregivers can assist by:

• Correcting vision and hearing deficits by ensuring that spectacles and hearing aids are worn and adjusted correctly
• Promoting mobility via walking aids and regular exercise
• Relieving pain by means of regular analgesia, physical exercise and change of position
• Minimizing incontinence through regular toileting regimes and incontinence aids
• Using short, simple sentences and making word or icon cards for people who do not share the local language

If caregivers are to meet these various needs of people with dementia in a way that is truly therapeutic, they must have a detailed knowledge of each person’s:
• Cultural and family background
• Personal life story
• Previous interests and skills
• Likes and dislikes (e.g., food, activities, personal care)
• Physical well-being

People with mild dementia can provide much of this information themselves. Family members will need to be questioned about the backgrounds of those with more severe levels of impairment.

The term “person-centered care” is used to describe a style of engaging with people with dementia that encapsulates all of the above points. There is evidence that behavioral symptoms are reduced when:
• Nursing home staff are trained in person-centered care (Chenoweth et al., 2009)
• Personal care is designed to maintain residents’ abilities and to help them compensate for lost ones (Wells et al., 2000)
• Residents are bathed in their preferred way while carers speak to them calmly and minimize discomfort (Sloane et al., 2004)

Nursing home staff can rate their ability to deliver dementia-sensitive care using the Person-centered Care Assessment Tool (P-CAT) (Edvardsson et al., 2010). The tool allows staff to rate the professional, organisational and environmental factors that promote or impede a focus on residents’ individuality and autonomy.

Assessment methods

When treating BPSD, success rates will be higher if a full assessment is made beforehand. To make sense of symptoms, and devise strategies to make their expression unnecessary, it is necessary to:
• Identify what symptom(s) most trouble the resident and present the greatest challenge to carers
• Describe each symptom in detail; note what exactly the resident does or says that is concerning
• Specify the Antecedents of Behaviors (the circumstances that spark them) and their Consequences (what makes them better or worse)—this is called the ABC approach
Caregivers often believe symptoms come ‘out of the blue’ but careful observation of the events immediately preceding them will usually identify trigger factors. Symptoms are rarely simple. Usually several factors are involved in triggering symptoms and the more caregivers understand their inter-relationship, the more likely it is that interventions will prove successful. The following examples use the ABC approach to understand symptoms:

- A resident is too confused to shower herself. She is incontinent of urine overnight and needs a shower each morning. When carers help her to undress and wash (Antecedent), she hits them and pushes them away (Behavior). Carers tend to leave her alone as a result (Consequence). This relieves her agitation temporarily but her groin area is becoming abraded through neglect.

- When another resident is left alone for long periods in the morning (Antecedent), he becomes anxious and irritable and asks repeatedly when his daughter will come to see him (Behavior). Staff members respond to his questions (Consequence). This helps only for a few minutes.

**Mapping symptoms**

Mapping the frequency and severity of symptoms shows patterns in occurrence during the day, from one day to another, as well as changes before and after an intervention is introduced. It provides an objective rating of what is happening over time. Symptoms can be mapped in the following ways:

- Keeping a daily diary, using the carer’s own words
- Graphing a symptom on paper, marking if it is absent or present to a mild, moderate or severe degree on an hour by hour (or shift by shift) basis
- Using a rating scale. The two scales used most often in research studies are the following:
  - The Cohen-Mansfield Agitation Inventory—CAMI (Cohen-Mansfield, 1991) rates the frequency of 29 individual behaviors (e.g., hitting, calling out) in the previous two weeks. A shorter 14-item version is also available.
  - The Neuropsychiatric Inventory (NPI) rates the frequency and severity of a wider range of symptoms including delusions, hallucinations, agitation, apathy, and sleep disturbance in the previous one month (Cummings, 1997).

**Treatment principles**

When devising an approach to help a person with a behavioral or psychological symptom, experts recommend that carers should:

- Address one symptom at a time
- Follow the ABC approach
- Measure the symptom before and after making an intervention to confirm that it is effective
- Start with a small achievable goal and proceed step-by-step
- Apply the intervention consistently. Do not expect immediate change, improvement takes time.
• Continually evaluate and modify plans. Decide in advance what “success” means for this person
• Think in advance of an alternative strategy if the first one fails

There is evidence that teaching family caregivers to follow these principles can prove just as effective as psychotropic medications in reducing agitation (Teri et al., 2000).

Further tips
It is important to respond sensitively and constructively when people with dementia feel anxious, frustrated or overwhelmed. Strategies that experts have often found to be successful include the following:
• Identifying situations that trigger distress and avoiding them whenever possible
• Recognizing that the person's stress levels are rising and taking action to prevent them escalating further
• Approaching an anxious, agitated person from the front
• Speaking at eye level, and using a gentle, non-threatening posture and tone of voice
• Telling the person what is happening and why
• Defusing the situation once stress levels rise by changing activities, tempo or space
• Avoiding arguments whenever possible as they usually make things worse
• If all else fails, telling an untruth (e.g., “Your daughter will be here later”) as a means of relieving distress
• Avoiding physical restraint since it can lead to escalating levels of agitation

Ensuring safety
It is important for carers to have the knowledge, skills and resources to maintain the safety of all concerned—the person with dementia, the carers themselves and co-residents:
• A medication box helps carers check that essential medications are being taken correctly
• People at risk of wandering and becoming lost should carry a card or wear a bracelet with their address and telephone number
• Gas or electrical appliances may need to be disabled if people use them dangerously
• Carers must know what to do and how to get help urgently if a situation becomes dangerous
• If a significant risk is identified, strategies should be written in the care plan in an obvious place.

Individual treatments
This section describes psychosocial treatments of physical agitation, aggression and anxiety. Treatments of specific symptoms are discussed later. There are now hundreds of published reports of different non-pharmacological treatments of BPSD (Opie et al., 1999; Cohen-Mansfield, 2001; O'Connor et al., 2009a; O'Connor et al., 2009b).
In most studies, a treatment is compared with “usual care”. If it proves superior, it is promoted as having a special therapeutic effect. In reality, its benefits might simply reflect the personal attention that follows from participating in a scientific study. For reasons of space, the focus here is on evidence from well-designed trials in which a treatment reduced agitation or distress better than personal attention. Only a small number of published reports met this requirement (O’Connor et al., 2009a). The fact that a treatment does not qualify for inclusion in this brief outline (e.g. pet therapy) does not mean that it lacks value. A lack of evidence is not the same as a lack of effectiveness.

The material presented below focuses more on treatments of physical agitation than anxiety and depression, reflecting researchers’ interests.

**Activity and recreation**

Enjoyable, meaningful activities improve quality of life, mood and behavior. Activities can take the form of daily chores, hobbies or shared pastimes. Two studies have shown that:

- Activities offering art, rhythm and touch led to greater contentment and interest (Beck et al., 2002)
- Recreational activities elicited more pleasure and interest when they were matched to people’s previous interests (Kolanowski et al., 2005).

**Aromatherapy**

Lavender (*Lavendula angustifolia*) and lemon balm (*Melissa officinalis*) have both been tested as treatments for BPSD. Lavender oil is quickly absorbed through skin and respiration (Jäger, 1992) and acts on brain neurotransmitter systems in a similar way to sedative medications (Elisabethsky et al., 1995). When administered to mice, they become much less active for approximately an hour (Buchbauer et al., 1993). The evidence from controlled trials is mixed but two trials found that:

- Agitated behaviors reduced in frequency when 2% lavender oil was sprayed in a dementia care unit (Holmes et al., 2002)
- Massage on the face and arms with lemon balm led to a reduction in agitated behaviors (Ballard et al., 2002).

**Family tape-recordings**

The voice or image of a family member can have a calming effect on confused nursing home residents who quickly forget visits. One study found that a 15-minute audiotape made by a family member reduced agitated behaviors when played through headphones (Garland et al., 2007).

**Music and sound**

Music can engage interest and generate positive emotions. It also provides an opportunity for enjoyable social interaction. Research studies found that:

- Music that was carefully matched to people’s interests reduced agitated behaviors more than “off the shelf” relaxing classical music (Gerdner, 2000)
• Playing soothing audiotapes of a mountain stream or ocean waves reduced verbally disruptive behaviors (Burgio et al., 1996)
• Live music resulted in higher rates of arousal, engagement and well-being than pre-recorded music (Sherratt et al., 2004)
• Playing tapes of people’s preferred music during baths reduced rates of verbal and physical aggression (Clark et al., 1998)

**One-to-one interaction**

Empathic, attentive contact with another person may be the key ingredient in many psychosocial interventions. In support of this view, one-to-one interaction with a therapist who sought to engage people in conversation, gentle exercise, a sensory kit or manual activities shaped by their interests and skills worked as well in reducing verbally disruptive behaviors as a family-made videotape (Cohen-Mansfield and Werner, 1997).

**Physical activity**

Physical activity lifts mood and has a calming effect in younger age groups. In a nursing home study, a daily, 30-minute active exercise program led to a greater improvement in mood than either a gentle walking group or a conversation group (Williams and Tappen, 2007).

**Treatment of particular symptoms**

**Exit-seeking**

Some people with dementia try leave their home or a residential facility without heed to their safety. This presents a challenge to carers to minimize risk while still encouraging activity and independence. Evidence shows that:

• The number of locked doors in residential facilities should be kept to a minimum since locking doors makes it more likely that residents will try to leave (Namazi and Johnson, 1992)

• Attempts to leave residential units are reduced if exit doors do not have glass panels and if doors and door handles are obscured so as not to draw residents’ attention (Dickinson et al., 1995)

**Repeated questioning**

Repeated questioning (e.g., “What time is my daughter coming?) can be stressful to caregivers. Suggested strategies include:

• Recognizing the worry that prompts the question (e.g., a fear of abandonment) and providing reassurance (“Your daughter phoned earlier. She’s really concerned about you.”)

• Giving comfort in a culturally-appropriate way (e.g., hand holding, neck massage)

• Starting an enjoyable activity
People with mild to moderate dementia who ask a question repeatedly (e.g., “What day is it”?) can be taught to look at a card in their pocket that has the answer written on it. Once the behavior is learned, the intervals between instructions are spaced further and further apart. This technique is called spaced retrieval (Malone et al., 2007).

**Sleep disturbance**

Dementia is sometimes accompanied by a profound disturbance of the daily sleep-wake cycle resulting in broken or limited sleep. Sleeping tablets sometimes have limited effectiveness.

There is evidence that a sleep hygiene program slightly reduces the length of time spent awake at night and greatly reduces the amount of time spent sleeping by day (Alessi et al., 2005). A sleep hygiene program includes the following steps:

- Encouraging activity during the day
- Having a set, personalized bedtime routine
- Keeping nighttime noise and light to a minimum
- Avoiding unnecessary nighttime interruptions

There is no strong evidence that bright light therapy assists with sleep-wake disturbances (Forbes et al., 2004).

**Physical environment**

A calm, supportive physical environment helps to prevent or minimize BPSD by the following means:

- Ensuring that help is readily available
- Encouraging independence while preserving safety
- Promoting meaningful activity and social engagement

Experts advise that these goals are best achieved by providing:

- Small, home-like residential units
- Ready access to staff members
- A range of shared areas with varied ambience
- Single bedrooms for most people
- Clearly marked access to conveniently situated bathrooms
- Adequate lighting
- A calm environment free of loud music and television
- Access to safe walking paths and gardens
- Maintenance of personal identity, background and culture through use of photographs, mementoes, furnishings and reading materials

Each residential facility is unique and it is difficult to prove that a single design feature has a distinct effect on residents’ mood, activity levels and independence. Even so, there is evidence that:

- Home-like environments with single bedrooms are linked to lower rates of anxiety and aggression (Zeisel et al., 2003)
• Residential facilities that offer privacy, a home-like setting, visual and tactile stimulation, and outdoor areas have lower rates of agitation and other symptoms (Bicket et al., 2010)
• Residents spend more time in settings enriched with pleasing sounds, smells and photographs (Cohen-Mansfield and Werner, 1998)

Fleming and Purandare (2010) give an overview of the relationship between the physical environment and the mental well-being of people with dementia.

Nursing home staff members can rate the quality of their physical environment (e.g., its opportunities for social interaction, levels of stimulation and provision for wandering) using the Environmental Audit Tool (Fleming, 2011).

Conclusions

• Many of the benefits of psychosocial treatments stem more from the person who delivers the treatment than from the treatment itself. This is not a problem. Any activity that is enjoyable, healthy and culturally appropriate is to be encouraged.
• The treatments outlined above do appear to have some additional specific benefits. These benefits tend to fade quite quickly once the treatment stops. Once again, this need not be a problem. Few symptoms are present continuously throughout the day. Some are present just at particular times (e.g., “sundowning”). Others arise just in particular circumstances (e.g., personal care). It makes sense, therefore, to target treatments at these times.
• There is good evidence that treatments work best when tailored to people’s interests and skills. For those with advanced dementia, this information must be sought from a family member.

References and recommended reading


Other resources

The following resources are suitable for family and professional caregivers:

Dementia Gateway

The British Social Care Institute for Excellence provides online modules on dementia care. Topics include communication, activities, nutrition and the physical environment. With respect to challenging behaviors, there is detailed information on constructive responses to aggression, repetitive questions, disorientation and refusal of help.

Alzheimer’s Australia

Alzheimer’s Australia publishes online fact sheets on a range of challenging behaviors including wandering, sundowning, aggression, agitation and disinhibited behaviors. Each two-page fact sheet addresses the causes of behaviors, prevention and recommended responses.
# 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).

- Medication is indicated for BPSD that are moderate to severe and that impact on a patient’s or caregiver’s quality of life, functioning, or that pose a safety concern, often in conjunction with non-pharmacological interventions.

- All patients should be informed of the potential risks associated with pharmacological treatments of BPSD and monitored accordingly.

- In elderly patients with dementia, dosages of medication will generally be lower than those used in younger patients and in older people, although the elderly are a heterogeneous group requiring an individualized approach to dosing.

- Antipsychotic medications are most effective in the treatment of psychotic symptoms (hallucinations, delusions), agitation, and aggression.

- Both atypical and typical antipsychotics appear to carry an increased risk for mortality and stroke in patients with dementia. These should be prescribed only after discussing risks and benefits, and their use should be re-evaluated frequently when prescribed.

- Atypical antipsychotics are preferred over typical antipsychotics for BPSD.

- Antidepressants may be used in for the treatment of agitation in dementia as well as for depression in dementia.

- Cholinesterase inhibitors and memantine may be useful in treating BPSD; these medications may also provide cognitive benefits unlike other medications.

- Anticonvulsant medications, especially carbamazepine, may be an option for the treatment of agitation when other medications have failed; current evidence does not favor the use of valproic acid.

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 precipitating or perpetuating factors for the observed behaviors. The clinical presentation and diagnostic criteria for BPSD are presented in Module 2, and etiology is discussed in Module 3. There have been several BPSD review articles (Sink et al., 2005a; Schneider et al., 1990; Schneider et al., 2006a; Herrmann and Lanctôt, 2007; Snowden et al., 2003; Bharani and Snowden, 2005; Trinh et al., 2003; Ballard et al., 2009a; Ballard et al., 2009b) and guidelines (Canadian Coalition for Seniors’ Mental Health, 2006b; American Geriatrics and American Association for Geriatric, 2003; Jeste et al., 2008; Herrmann et al., 2007a) that would serve to provide additional details on this topic to complement The IPA Complete Guides to BPSD.
• In general, non-pharmacological approaches are the first-line treatment for BPSD (see Module 5)
• Medications are indicated for BPSD symptoms that are refractory to non-pharmacological interventions, severe, or jeopardize the safety of a patient or others, often in conjunction with non-pharmacological interventions
• Prescribing must involve an assessment of patient capacity, informed consent, and judicious dosages
• Dose adjustment should involve slow and cautious dose titration, with careful monitoring for the emergence of side effects
• When using drugs in a population with dementia, due consideration must be given to the age and disease-related changes in the pharmacokinetics, pharmacodynamics, nutritional status, and renal and hepatic function
• Older adults with dementia are more sensitive than younger individuals to the side effects of many drugs, particularly medications that can cause sedation, cognitive-impairment, central anticholinergic side effects, or extrapyramidal symptoms (EPS)
• Many dementia patients, especially those with dementia with Lewy bodies and Parkinson’s disease dementia, will demonstrate increased sensitivity to antipsychotics (typical antipsychotics in particular) due to deficits in dopaminergic pathways
• 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 likely to respond to pharmacotherapy?
  – Which class 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 discussion of the risks and benefits of treatment with the patient or a substitute decision maker, and when symptoms have been found to:
• Have no physical cause
• Not be caused by the effects of other medication
• Not be caused by environmental factors
• Have failed to 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 research and practice that particular symptoms or behaviors respond to a particular drug intervention. The use of different pharmacological agents in the management of BPSD is outlined in Table 6.1.
Table 6.1: Pharmacological therapy and BPSD.

<table>
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<th>Drug category</th>
<th>Target symptom</th>
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<td>Trazodone</td>
<td>Sleep-wake cycle disturbances, agitation, aggression, anxiety, depressive syndromes</td>
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<td>Depressive syndromes, agitation, irritability, psychosis</td>
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<td>Depressive syndromes</td>
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<tr>
<td>Tricyclic antidepressants (TCAs)</td>
<td>Depressive syndromes</td>
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<td>Cognitive Enhancers</td>
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<tr>
<td>Cholinesterase inhibitors</td>
<td>Cognition, apathy, aberrant motor behavior, anxiety, depressive syndromes, psychosis (delusions, hallucinations)</td>
</tr>
<tr>
<td>Memantine</td>
<td>Cognition, aggression, agitation, irritability, psychosis</td>
</tr>
<tr>
<td>Other Medications</td>
<td></td>
</tr>
<tr>
<td>Anticonvulsants</td>
<td>Agitation, aggression, manic-like symptoms, sleep disturbance</td>
</tr>
<tr>
<td>Benzodiazepines</td>
<td>Anxiety, agitation, sleep disturbance</td>
</tr>
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</table>

It is important to identify target symptoms or behaviors, and to use medications that may address several different symptoms to avoid unnecessary polypharmacy (sedating atypical antipsychotic for individuals with agitation, psychosis, and sleep disturbance).

Drug treatment for BPSD should be time-limited when possible. Drug dosages should be reviewed and reduced or discontinued when possible, and all psychotropics should be reviewed at a minimum of every three months. The outcome of a pharmacological treatment should be monitored on a routine basis for both efficacy and side effects.

**Antipsychotics**

There are two broad categories of antipsychotic medications that are used in dementia patients with BPSD:

1. Atypical antipsychotics have broad, drug specific effects on dopaminergic, serotonergic, and other receptors with a decreased propensity to cause EPS. Clozapine was the first atypical antipsychotic available, but there are now a number of agents available including risperidone, olanzapine, quetiapine, aripiprazole, and ziprasidone.

2. Typical (conventional) antipsychotics—Actions are primarily mediated through dopamine D2-antagonism and are more likely to cause extrapyramidal symptoms (EPS). Examples of such agents are haloperidol, perphenazine, and loxapine.
Typical antipsychotics were once the most common psychotropic medication prescribed to agitated patients in nursing homes and long-stay institutions (Ray et al., 1980; Gilleard et al., 1983). However, only a modest evidence base exists to support their use, and atypical antipsychotics are now being prescribed much more frequently to this population (Kamble et al., 2008).

**Atypical antipsychotics**

There are several randomized controlled double-blind studies to suggest that antipsychotics are effective in the treatment of BPSD and may have improved side effect profiles when compared to typical antipsychotics (De Deyn et al., 1999; Chan et al., 2001). In particular, atypical antipsychotics are associated with less EPS and a lower propensity to cause tardive dyskinesia.

**Efficacy of atypical antipsychotics.** There are published randomized controlled trials for risperidone, olanzapine, aripiprazole, and quetiapine for the treatment of BPSD in older adults with Alzheimer’s disease. There have been several systematic reviews and meta-analyses of atypical antipsychotics for BPSD (Ballard and Waite, 2006; Schneider et al., 2006a; Lee et al., 2004; Herrmann and Lanctôt, 2007; Sink et al., 2005b) that contain additional information on unpublished studies.

The largest trial to-date investigating the efficacy and safety of atypical antipsychotics for BPSD is the CATIE-AD trial. This multicenter trial compared risperidone, olanzapine, quetiapine, and placebo for agitation in Alzheimer’s disease. The primary outcome was time to discontinuation of therapy for any reason. Overall rates of discontinuation for any cause were similar among the four groups, although the time to discontinuation of therapy for lack of efficacy favored olanzapine and risperidone (Schneider et al., 2006b) over placebo and quetiapine. Symptoms most likely to respond to treatment were anger, aggression, and psychosis (Sultzzer et al., 2008).

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 (Katz et al., 1999; De Deyn et al., 1999; Brodaty et al., 2003; Chan et al., 2001). Risperidone at this dose is well tolerated and has an EPS profile similar to placebo (Katz et al., 1999; De Deyn et al., 1999; Brodaty et al., 2003) and superior to haloperidol (De Deyn et al., 1999; Chan et al., 2001). There is also at least one published, randomized controlled trial that did not demonstrate significant benefit of risperidone over placebo (Mintzer et al., 2006). Another trial comparing flexibly dosed risperidone (0.5-2.0 mg) or olanzapine (2.5-10 mg) to placebo found no significant benefit of either active drug when compared to placebo (Deberdt et al., 2005). The rate of discontinuation was lowest in the placebo group, and olanzapine had significantly higher rates of discontinuation when compared to both placebo and risperidone.

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 5 mg dose showed greater efficacy than the 10 mg dose (Street et al., 2000). A second trial of olanzapine found that olanzapine in doses of 5 and 7.5 mg did not result in significant improvement in BPSD when compared to placebo in the primary outcome of the study (De Deyn et al., 2004).
A fixed dose, randomized controlled trial compared quetiapine 200 mg daily, 100 mg daily, and placebo for BPSD. The group receiving 200 mg daily had improvement over the placebo group on the primary outcome (Zhong et al., 2007). A second randomized controlled trial of quetiapine (mean dose 96 mg), haloperidol (mean dose 1.9 mg), or placebo did not find any significant difference among the three groups on global measures of BPSD, although agitation may have been improved with the two drug groups when compared to placebo (Tariot et al., 2006). Quetiapine tended to be better tolerated than haloperidol. A third trial of quetiapine (50–100 mg) compared to rivastigmine and placebo did not find that either active treatment was superior to placebo. Greater cognitive decline was observed with quetiapine when compared to placebo (Ballard et al., 2005).

At least two randomized placebo-controlled trials of aripiprazole for BPSD have been completed. The first found no difference in the primary endpoint of psychosis as measured on the NPI or on global measures of change (De Deyn et al., 2005). The second trial found that 10 mg of aripiprazole was superior to placebo on measures of psychosis, agitation, and global improvement, while lower doses (2 mg or 5 mg) were not effective (Mintzer et al., 2007). Adverse event rates were not statistically significant between the treatment groups.

Open-label trials of ziprasidone have also demonstrated efficacy, although adverse events were also commonly observed (Rocha et al., 2006).

**Discontinuation of antipsychotics.** 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). There are several randomized, placebo-controlled studies examining the effects of discontinuing long-term treatment with antipsychotics (van Reekum et al., 2002; Cohen-Mansfield et al., 1999; Ruths et al., 2008; Ballard et al., 2008; Devanand et al., 2012). Most studies have found that many individuals can have antipsychotics safely discontinued without worsening of behavioral symptoms. One recent trial, however, reported a significantly increased risk of relapse up to four months after discontinuation of risperidone in patients with psychosis or agitation and aggression (Devanand et al., 2012). Predictors of successful discontinuation antipsychotics include lower daily doses of antipsychotics (van Reekum et al., 2002; Ruths et al., 2008) and lower baseline severity of behavioral symptoms (Ballard et al., 2008). Most studies have examined relatively short-term behavioral outcomes, although one study found no significant difference in behavioral symptoms following discontinuation at six months (Ballard et al., 2008). No differences in other outcomes, including cognition and adverse events, were noted between continuation and discontinuation groups in the placebo-controlled trials (Declercq et al., 2013), but long-term mortality follow-up data from one study indicated that discontinuation of antipsychotics was associated with reduced mortality at 12, 24, and 36 months (Ballard et al., 2009c).

**Side effect profile of atypical antipsychotics.** Like all medications, side effects need to be monitored during drug treatment with atypical antipsychotics. Most atypicals may be associated with dyslipidemia, impaired glucose tolerance, and weight gain. The risk of weight gain may be greatest in females treated with olanzapine or quetiapine, and olanzapine may be associated with the greatest adverse effects on cholesterol (Schneider et al., 2009). All antipsychotics are associated with an increased risk of falls and fractures. In addition, clozapine has significant anticholinergic and postural hypotensive effects, and it is associated with a
risk of agranulocytosis that requires weekly white blood cell count monitoring. Olanzapine, like clozapine, also possesses anticholinergic activity. Risperidone can be associated with the emergence of EPS, postural hypotension, and sedation at higher doses. Quetiapine can be associated with sedation and postural hypotension. Ziprasidone can also cause prolongation of the QT interval, although it likely has the most benign metabolic side effect profile.

**Mortality and cerebrovascular events with antipsychotics.** European, American, and Canadian regulatory agencies have issued warnings regarding an increased risk of adverse events in patients with dementia receiving these drugs for management of BPSD. The initial 2005 warning issued by the United States Food and Drug Administration (FDA, 2005) was based upon a meta-analysis of 17 trials of atypical antipsychotics in patients with dementia. The trials showed an increased relative risk of death of approximately 1.7, mainly due to vascular or infectious causes (Schneider et al., 2005). The risk of ischaemic stroke in particular was emphasized by the FDA based upon studies predating this meta-analysis. The FDA warning was subsequently extended to cover all antipsychotics (FDA, 2008) after retrospective population-based studies of American (Wang et al., 2005) and Canadian (Schneeweiss et al., 2007; Gill et al., 2007) data demonstrated that typical antipsychotics also showed a similar increased risk of death. More recent studies have even suggested that the risk of death with typical antipsychotics may even be greater than with the atypical ones (Liperoti et al., 2009; Hollis et al., 2007) and that those who remain on long-term (12 months and more) antipsychotic therapy have an increased and persistent risk of mortality with decreased survival at up to 3 years follow-up (Ballard et al., 2009).

It should be noted that, although antipsychotics are associated with increased risk of death, the absolute increase in mortality is between 1–2% (Meeks and Jeste, 2008). A prudent recommendation is that antipsychotics should be used more judiciously than they have been in the past. Studies examining rates of antipsychotic prescribing in the United States after the FDA warnings demonstrated that the prescription of these medications for patients with BPSD has decreased (Dorsey et al., 2010). However, some authors believe that current prescription practices are still not cautious enough (Rochon and Anderson, 2010), and certainly more research needs to be urgently conducted regarding these concerns. In the meantime, before initiating the use of these medications, patients and substitute decision-makers should be informed about the warnings regarding them and the data supporting these warnings.

**Guidelines for prescribing antipsychotics in BPSD.** On the basis of evidence from the literature, the following clinical guidelines for the use of antipsychotics are recommended:

- Use in conjunction with non-pharmacological interventions
- Moderate to severe BPSD, especially agitation, aggression, or psychosis
- Discuss risk of common side effects (e.g., falls, postural hypotension, sedation) and less common but serious side effects (e.g., cerebrovascular accidents, mortality)
- Use antipsychotics for as short a time period as possible and attempt to reduce dosages and discontinue antipsychotics when possible
- Check for a history of antipsychotic sensitivity, and consider the diagnosis of dementia with Lewy bodies before prescribing any antipsychotic
The suggested starting doses and maximum dosages are listed in Table 6.2. In general, increases in dosage should occur at a maximum once weekly unless more rapid dose titration is required. Patients should be monitored carefully for the development of adverse effects including EPS, postural hypotension, anticholinergic side effects, sedation, and falls.

Set duration for treatment and monitor. A duration of 12-weeks treatment is recommended and should be reviewed. If a 4- to 6-week trial of one agent at an adequate dose fails to decrease the frequency, severity, or impact of a target symptom, a trial of a second agent would be indicated.

**Table 6.2: Clinical recommendations for dosing of typical and atypical antipsychotics for BPSD**

<table>
<thead>
<tr>
<th>Drug</th>
<th>Starting Dose (mg)</th>
<th>Dose range (mg) Schedule</th>
</tr>
</thead>
<tbody>
<tr>
<td>Risperidone</td>
<td>0.25</td>
<td>0.5–2 once daily</td>
</tr>
<tr>
<td>Olanzapine</td>
<td>2.5</td>
<td>5–10 once daily</td>
</tr>
<tr>
<td>Aripiprazole</td>
<td>2.0</td>
<td>5–10 daily</td>
</tr>
<tr>
<td>Quetiapine</td>
<td>25.0</td>
<td>25–150 daily divided doses</td>
</tr>
<tr>
<td>Haloperidol</td>
<td>0.5</td>
<td>0.5–2 once daily</td>
</tr>
<tr>
<td>Ziprasidone*</td>
<td>20.0</td>
<td>40–80 in divided doses, administered with meals</td>
</tr>
<tr>
<td>Clozapine*</td>
<td>6.25</td>
<td>12.5–100 once or twice daily</td>
</tr>
</tbody>
</table>

*Information from open-label trials only

**Typical antipsychotics**

Three systematic reviews have evaluated the effects of typical antipsychotics on symptoms of BPSD. The first review included 17 placebo-controlled studies, 7 of which were of sufficient quality to be included in meta-analysis (Schneider et al., 1990). The doses of medications in these studies were modest (chlorpromazine equivalent 66–267/mg day). There was a small, but statistically significant difference between all antipsychotics and placebo in the meta-analysis. At the time of this meta-analysis, haloperidol and thioridazine were the most commonly utilized antipsychotics for BPSD. Meta-analysis comparing thioridazine or haloperidol to comparator antipsychotics did not find any significant difference between these two agents and all other antipsychotics.

A more recent meta-analysis included 16 studies of typical antipsychotics (Lanctôt et al., 1998). Overall, 61% of individuals treated with typical antipsychotics had a clinical response, compared to 34% of individuals who received placebo. The trials tended to have fair quality in terms of potential risk of bias. Dosages of medication were relatively low in most studies, defined by daily dose equivalents. There were no differences noted in response rates for different classes of antipsychotic potency. However, higher rates of side effects were observed for all antipsychotics when compared to placebo, although there were no differences in trial withdrawals. There was no significant difference in side effects or drop-outs for butyrylphenones when compared to other antipsychotics.
A review of five studies examining haloperidol for agitation in dementia found that haloperidol was effective in reducing symptoms of aggression but not overall levels of agitation (Lonergan et al., 2002). There was no statistically significant difference in dropout rates for haloperidol when compared to placebo.

There are relatively few studies comparing typical antipsychotics to atypical antipsychotics. Most trials have found similar efficacy for typical antipsychotics when compared to atypical antipsychotics, although some studies have found greater efficacy of atypicals when compared to typicals. Atypical antipsychotics also seem to be associated with less extrapyramidal side effects when compared to typical antipsychotics.

Based on the evidence (Schneider et al., 1990; 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 typical antipsychotic medications include agitation, hallucinations, and hostility.

**Side effect profile of typical antipsychotics.** The most common side effects of antipsychotics are the following:

- Extrapyramidal side effects (EPS) (e.g., bradykinesia, tremor, mask-like facies), especially with high-potency conventional agents such as haloperidol and thiothixene, although EPS can occur with low-potency typical antipsychotics as well.
- Postural hypotension and anticholinergic side effects (e.g., dry mouth, constipation, urinary retention, and delirium) are more likely with low-potency conventional agents such as chlorpromazine.
- Elevated risk of tardive dyskinesia with long-term treatment. The estimated incidence of tardive dyskinesia in the elderly following conventional neuroleptic treatment is 25% following one year of treatment (Woerner et al., 1998). For this reason an 8–12 week (time-limited) exposure of dementia patients to typical antipsychotics 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 treat drug-induced EPS is discouraged, because they are likely to increase delirium and other anticholinergic adverse effects.

**Effects of typical antipsychotics on cognition and function.** It is possible that long-term exposure to conventional neuroleptics, while improving behavioral disturbance, results in a deterioration in functional ability and a progression of dementia. Treatment with haloperidol over 6–8 weeks was associated with a decline in cognition as measured with the Mini-Mental State Examination (MMSE) (Devanand 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 cognitive deterioration could also be explained by a worsening of cognition and functional abilities with typical antipsychotics (McShane et al., 1997; Stern et al., 1987; Chui et al., 1994). It has also been suggested that the worsening of cognitive impairment in patients with Alzheimer’s disease could result through central anticholinergic side effects of low-potency conventional antipsychotics.
Antidepressants

Trazodone. Serotonin has an important role in the development of behavioral symptoms in dementia (Lawlor, 1990), and a number of antidepressants have been utilized for BPSD. Both open-label studies (Pinner and Rich, 1988; Aisen et al., 1993; Lawlor et al., 1994) and three placebo-controlled trials (Lawlor et al., 1994; Sultzter et al., 1997; Teri et al., 2000) found that trazodone may have modest effects for the treatment of agitation in patients with BPSD. Trazodone has sedative properties and thus may also be useful in treating sleep disturbances associated with dementia. Doses varying from 50–250 mg/day have been used in studies, and the recommended dose range for patients with severe BPSD would generally not exceed 300 mg/day. The main side effects of trazodone are somnolence and postural hypotension, and more rarely trazodone can be associated with priapism.

Selective serotonin reuptake inhibitors (SSRIs). Placebo-controlled trials of citalopram (Nyth and Gottfries, 1990) and sertraline (Finkel et al., 2004) have found some benefit on symptoms of BPSD while one small trial of fluoxetine was negative (Auchus and Bissey-Black, 1997). Studies comparing fluoxetine (Auchus and Bissey-Black, 1997) and sertraline (Gaber et al., 2001) to haloperidol found similar effects for antidepressants with trends towards improved tolerability. Studies of citalopram compared to perphenazine (Pollock et al., 2002) and risperidone (Pollock et al., 2007) have also shown that the effects of citalopram are similar to antipsychotics for BPSD. A recent pilot study comparing escitalopram and risperidone found both effective at reducing behavioral and psychotic symptoms. Although improvement was earlier with risperidone, escitalopram was better tolerated (Barak et al., 2011).

Discontinuation of antidepressants. Few studies have examined the effect of withdrawing antidepressants in patients with dementia. A small, open-label trial and a subsequent placebo-controlled discontinuation trial have suggested that selective serotonin reuptake inhibitors can be safely discontinued in most patients (Bergh and Engedal, 2008; Bergh et al., 2012). In the placebo-controlled trial, the majority of nursing home patients on selective serotonin reuptake inhibitors tolerated antidepressant discontinuation without change however a small but significant increase in depressive symptoms was noted (Bergh et al., 2012). Patients with prior history of depressive disorders were excluded but the indication for the antidepressant treatment was not specified. An increase in neuropsychiatric symptoms was also observed but the difference did not reach significance.

Side effects associated with SSRIs can include gastrointestinal upset, diarrhea, akathisia, restlessness, sleep disturbance (insomnia/somnolence), hyponatremia, and increased risk of bleeding, especially in patients taking anti-platelet agents. SSRIs are also associated with falls and fractures.

Antidepressants used in dementia patients with depression. A randomized placebo-controlled study found that paroxetine was as effective, and better tolerated, than imipramine in treating depression in dementia (Katona et al., 1998). An initial study of sertraline in treating dementia found significant benefits over placebo (Lyketsos et al., 2000); however, a recent large-scale replication of this trial failed to show significant benefit for sertraline over placebo (Rosenberg et al., 2010). Another large trial of sertraline (or sertraline) and mirtazapine in combination
similarly failed to demonstrate an advantage over placebo (Banerjee et al., 2011), and an older placebo-controlled trial of sertraline also failed to show a significant benefit (Magai et al., 2000). A placebo-controlled study of fluoxetine for depression in dementia also failed to find significant benefit of drug over placebo (Petracca et al., 2001).

A systematic review concluded that due to small sample sizes and few trials of newer and more commonly used antidepressants, evidence to confirm the efficacy of antidepressants in treating depression in dementia was insufficient (Bains et al., 2009). Likewise, results of a more recent meta-analysis were suggestive but did not confirm benefit, although the authors noted that this may reflect the paucity of evidence as opposed to ineffectiveness (Nelson and Devanand, 2009).

There is anecdotal evidence supporting the use of tricyclic antidepressants in depressed dementia patients (Reynolds et al., 1987). Results of a trial with imipramine (Reifler et al., 1989) for depression in dementia were negative, while clomipramine (Petracca et al., 1996) showed benefit over placebo. Tricyclic antidepressants are associated with problematic and frequent side effects in dementia patients, and must be used with caution. Tricyclic antidepressants can cause side effects including postural hypotension, blurred vision, urinary hesitancy and intracardiac conduction defects, and central anticholinergic side effects including delirium and falls. If tricyclic antidepressants are to be used in depressed dementia patients, secondary (e.g., nortriptyline, desipramine) rather than tertiary amines (e.g., amitriptyline, doxepin) are preferred, due to better tolerability.

When an antidepressant is selected, overall tolerability as well as favorable effects on anxiety, sleep disturbance, and agitation should also be considered. Mirtazapine may also be a useful treatment for use in depressed patients with dementia, given its sedative, anxiolytic, and appetite-stimulating properties (Raji and Brady, 2001; Cakir and Kulaksizoglu, 2008).

In addition, other placebo-controlled trials carried out with antidepressants such as 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 (Roth et al., 1996).

**Antidepressant dosing recommendations.** If an antidepressant is to be prescribed, selective serotonin reuptake inhibitors should be used as first line agents. Like all medications in this population, doses should start low and be increased gradually. A dosing schedule for selected antidepressants is shown in Table 6.3. Patients with depression should be treated for one to two years to prevent relapse (Canadian Coalition for Seniors’ Mental Health, 2006a).

The following antidepressants should be preferentially used in patient with dementia due to decreased anticholinergic activity, decreased potential for drug-drug interactions, and decreased likelihood of accumulation in renal or hepatic impairment: citalopram, escitalopram, sertraline, venlafaxine, or mirtazapine.
Table 6.3: Dosing schedule for selected antidepressants in patients with dementia

<table>
<thead>
<tr>
<th>Drug</th>
<th>Starting Dose (mg)</th>
<th>Dose range (mg) Schedule</th>
</tr>
</thead>
<tbody>
<tr>
<td>Trazodone</td>
<td>25</td>
<td>50–300</td>
</tr>
<tr>
<td>Citalopram</td>
<td>10</td>
<td>10–40</td>
</tr>
<tr>
<td>Escitalopram</td>
<td>5</td>
<td>10–20</td>
</tr>
<tr>
<td>Sertraline</td>
<td>25</td>
<td>50–100</td>
</tr>
<tr>
<td>Venlafaxine</td>
<td>37.5</td>
<td>75–150</td>
</tr>
<tr>
<td>Mirtazapine</td>
<td>15</td>
<td>15–45</td>
</tr>
<tr>
<td>Duloxetine</td>
<td>20</td>
<td>20–60</td>
</tr>
<tr>
<td>Bupropion</td>
<td>100</td>
<td>150–300</td>
</tr>
<tr>
<td>Moclobemide</td>
<td>150</td>
<td>150–600</td>
</tr>
<tr>
<td>Nortriptyline</td>
<td>10</td>
<td>25–100</td>
</tr>
</tbody>
</table>

Cognitive enhancers

**Cholinesterase inhibitors.** Three cholinesterase inhibitors (donepezil, galantamine, and rivastigmine) are currently indicated for the treatment of cognitive symptoms in Alzheimer’s disease, where they have proven clinically modest effects on dementia at various levels of severity (Birks, 2006). These medications are used “off-label” to treat BPSD.

There has been one trial of cholinesterase inhibitors for the treatment of BPSD. This trial studied the effect of donepezil 10 mg daily on symptoms of agitation during a 12-week trial. The study failed to demonstrate a significant effect of donepezil on treating symptoms of agitation in individuals with Alzheimer’s disease (Howard et al., 2007b) as measured by change in symptoms of agitation or proportion of individuals with significant improvement in agitation.

A recent, systematic review of 14 randomized controlled studies examining the use of cholinesterase inhibitors in BPSD found three studies that showed a significant effect of cholinesterase inhibitors on reducing BPSD as measured on NPI scores (Rodda et al., 2009). However, the eleven other trials reviewed showed no significant reduction of various BPSD for cholinesterase inhibitors when compared to placebo. Included among the negative trials was the only prospective trial to examine the effect of cholinesterase inhibitors on BPSD as a primary outcome (Howard et al., 2007a). A meta-analysis of nine randomized trials found that cholinesterase inhibitors were statistically significant over placebo in reducing NPI scores, but the magnitude of the effect was of questionable clinical significance (Campbell et al., 2008). The authors noted that the result became non-significant when only trials examining moderate-to-severe dementia were analyzed. A recent observational study of 938 Italian patients starting cholinesterase inhibitors for cognitive enhancement failed to show any improvement in BPSD symptom measures at 36 weeks, although the lack of a comparator group means that this study could not address whether the patients would have deteriorated more rapidly if not taking the medications (Santoro et al., 2010). Importantly, there were no differences shown among the three different medications.
Clinical observation suggests that cholinesterase inhibitors may be useful in targeting specific BPSD symptoms. Subgroup analyses of larger trials, and uncontrolled studies that have specifically investigated specific symptoms in addition to global measures of BPSD, suggest that apathy, aberrant motor behavior, hallucinations and delusions, and anxiety and depression may all be specifically improved with cholinesterase inhibitors (Gauthier et al., 2002; Feldman et al., 2005; Holmes et al., 2004; Aupperle et al., 2004; Cummings et al., 2004). The reviews mentioned earlier look more at global measures and may not capture this pattern of symptom response. There is also some suggestion that rivastigmine may be more useful in reducing hallucinations in Lewy body disease compared to Alzheimer’s disease, although the evidence to support this is preliminary (Rozzini et al., 2007).

Additional studies have found that withdrawal of cholinesterase inhibitors may lead to worsening of BPSD. A trial of donepezil in participants with Alzheimer’s disease and significant BPSD received open-label treatment for 12 weeks after which they were randomized to either placebo or continued treatment (Holmes et al., 2004). Individuals who received continued treatment with donepezil had decreased levels of BPSD when compared to placebo.

All three of the cholinesterase inhibitors are initially prescribed at subtherapeutic doses, on a slow dose-escalation regimen, in order to habituate patients to any potential side effects. The dosing schedules allow achievement of steady plasma levels of the medication before proceeding to a higher dose. A transdermal rivastigmine patch that has recently become available in some countries was equivalent to oral rivastigmine in the treatment of cognitive symptoms, and patients reported fewer gastrointestinal side effects (Winblad et al., 2007).

Common side effects of cholinesterase inhibitors include gastrointestinal symptoms such as diarrhea, gastrointestinal upset, and anorexia. Cholinomimetic cardiac effects have the potential to exacerbate pre-existing arrhythmias, including heart block. Some clinicians advocate obtaining an electrocardiogram prior to the prescription of these medications.

**Memantine.** Memantine is an NMDA glutamate receptor antagonist that is moderately effective in the symptomatic treatment of cognitive symptoms of dementia. As with cholinesterase inhibitors, there is a modest but growing body of evidence suggesting that this medication may also be useful in treating concurrent BPSD.

As of yet, only two prospective trials have examined the use of memantine in treating BPSD as a primary outcome. A randomized placebo-controlled trial of memantine added to donepezil in institutionalized patients with AD and clinically significant agitation found no effect of memantine on the CMAI score at 6 or 12 weeks. A statistically significant reduction in NPI score, a secondary outcome, favored memantine, but the clinical relevance of the 7–10 point decrease compared to placebo remained unclear as no significant change in global clinical improvement was noted (Fox et al., 2012). A similar trial in community dwelling AD patients with agitation and aggression at baseline showed no significant benefit of memantine compared to placebo on NPI score or secondary measures of behavior but lacked statistical power to detect an effect (Hermann et al., 2013).
Data from retrospective analyses and secondary outcome of trials provide additional information on the potential effects of memantine on BPSD (Grossberg et al., 2009; Cummings et al., 2006; Gauthier et al., 2005; Wilcock et al., 2008; Gauthier et al., 2008; Winblad and Poritis, 1999; van Marum, 2009). In a recent study in patients with moderate to severe AD, memantine was associated with a statistically significant four point reduction on the NPI as compared to placebo, while a meta-analysis of five trials (including three previously unpublished trials) concluded that memantine treatment was associated with a two point reduction on the NPI (Howard et al., 2012; Maidment et al., 2008). This was consistent with the results obtained in the Cochrane review sub-analysis looking at the effects of memantine for treating BPSD (McShane et al., 2006). The clinical significance of such a modest reduction in NPI scores is unclear. Studies that have investigated individual symptoms suggest that memantine can be useful in treating specifically delusions and hallucinations, agitation and aggression, and irritability (Cummings et al., 2006; Gauthier et al., 2008; Wilcock et al., 2008). In the largest of these studies, the effect size of memantine on agitation was approximately equivalent to that seen for antipsychotics (Wilcock et al., 2008). Importantly, one large observational study performed in France demonstrated that prescribing memantine resulted in reduced prescription of other psychotropic medications (Vidal et al., 2008), which provides further indirect evidence of its usefulness.

In some studies it has been observed that memantine, when compared to placebo, appeared to delay the emergence of BPSD, especially agitation, in patients without agitation at baseline (Wilcock et al., 2008; Gauthier et al., 2008). This has also been observed in patients who were concurrently taking donepezil (Cummings et al., 2006). These observations were from retrospective, post-hoc analyses, and need confirmation in prospective controlled trials. Thus, memantine may be effective in delaying the emergence of agitation, although this drug should not be prescribed with only this goal in mind.

Memantine is generally well-tolerated with the most commonly reported side effects being constipation, somnolence, dizziness, hypertension, headache, and anorexia. Confusion and anxiety may also arise as side effects of this treatment. In some cases, memantine may precipitate psychosis, especially in patients who have dementia with Lewy bodies (Ridha et al., 2005; Menendez-Gonzalez et al., 2005). Thus, while memantine is potentially useful for the treatment of BPSD, it also has the potential to precipitate such symptoms.

Anticonvulsants

Anticonvulsants may represent a useful alternative in cases where medications from other drug classes are found to be ineffective. Limited evidence for their efficacy comes from open-label studies, as well as some randomized controlled trials as reviewed in other articles (Konovalov et al., 2008; Amann et al., 2009). In general, the older anticonvulsants, especially carbamazepine, have the most evidence and experience for use in BPSD, but evidence is slowly beginning to accumulate for the use of some of the newer anticonvulsants.

Carbamazepine. Case reports (Essa, 1986; Leibovici and Tariot, 1988; Patterson, 1988; Marin and Greenwald, 1989), as well as open-label prospective studies (Gleason and Schneider, 1990; Lemke and Stuhlmann, 1994; Tariot et al., 1994) suggested that carbamazepine can be used to treat aggression, hostility, agitation, and mania-like symptoms. There is a case report of
its use for treating sexual disinhibition (Freymann et al., 2005). There have also been smaller randomized controlled trials examining this drug showing an effect on aggression, but these were open-label or had other methodological limitations (Olin et al., 2001; Cooney et al., 1996; Tariot et al., 1998). Importantly, this drug has been studied in patients who failed to respond to neuroleptics, where it was found to be useful in open-label studies (Lemke and Stuhlmann, 1994; Gleason and Schneider, 1990) and one randomized controlled trial (Olin et al., 2001). Thus, there is limited evidence that carbamazepine may be useful in BPSD, particularly in treating aggression and agitation. However, its side effects and drug interactions can, at times, limit the usefulness of this drug. Carbamazepine may be associated with a decreased risk of mortality when compared to antipsychotics in at least one large observational study (Hollis et al., 2007).

**Valproic acid.** Case reports have suggested that valproic acid preparations were useful in controlling aggression, agitation, and other mania-like symptoms in Alzheimer’s disease (Sandborn et al., 1995; Takahashi and Akagi, 1996) and vascular dementia (Buchalter and Lantz, 2001). This observation has been repeated in several larger retrospective case series (Sival et al., 1994; Narayan and Nelson, 1997; Kunik et al., 1998; Meinhold et al., 2005) and small open-label trials (Lott et al., 1995; Mellow et al., 1993; Haas et al., 1997; Porsteinsson et al., 1997; Sival et al., 2004; Forrester et al., 2007; Kasckow et al., 1997; Herrmann, 1998; Porsteinsson et al., 2003), mainly in patients with Alzheimer’s disease. Some studies have suggested that patients on valproate required lesser doses of antipsychotics (Narayan and Nelson, 1997; Meinhold et al., 2005). However, some studies also reported that patients suffered side effects from valproate, especially somnolence and ataxia (Forrester et al., 2007).

There have been five prospective, blinded, randomized controlled trials carried out examining the use of valproic acid derivatives for the treatment of agitation and mania-like symptoms (Porsteinsson et al., 2001; Tariot et al., 2001; Sival et al., 2002; Tariot et al., 2005; Herrmann et al., 2007b). None of these have shown a statistically significant effect of valproic acid to reduce BPSD, although one showed a trend toward reduced agitation (Porsteinsson et al., 2001). More importantly, most of these randomized controlled trials revealed a trend toward greater numbers of adverse events (Tariot et al., 2001; Konovalov et al., 2008). It would therefore appear that despite some promising observational evidence, the best evidence available does not support the use of valproic acid in the management of BPSD (Lonergan and Luxenberg, 2009).

**Other anticonvulsants.** A double-blind, randomized, placebo-controlled trial has been carried out examining the use of oxcarbazepine to treat agitation in patients with dementia (Sommer et al., 2009). This trial, which was among the most methodologically sound trials examining anticonvulsants for BPSD, did not show any significant effect.

Several case reports and case series have reported success using gabapentin to treat BPSD (Kim et al., 2008). In most patients, sedation is the main side effect. As a cautionary note, there has been a report of two patients with dementia with Lewy bodies who demonstrated a dramatic worsening of their illness (Rossi et al., 2002). Gabapentin may present a useful alternative in patients with agitation, hypersexuality, or sleep disturbance who are not responding to other classes of medication, but much more research is needed on its use.
Case reports (Devarajan and Dursun, 2000; De Leon, 2004; Tekin et al., 1998) and retrospective reviews (Aulakh et al., 2005) have suggested that lamotrigine may also be useful in treating BPSD. In all of the studies, lamotrigine was well tolerated. It can be prescribed at dosages of 12.5–25 mg daily, increasing up to 300 mg-per-day divided in two doses.

Topiramate has been studied in one open-label retrospective study of 15 dementia patients with BPSD (Fhager et al., 2003). It was used as monotherapy or as adjunctive therapy in doses ranging from 25–150mg per day, and caused a significant reduction in agitation.

A recent retrospective, open-label study of 37 patients with mania-like symptoms (defined as disinhibition, emotional lability, irritability, aggression, and agitation) refractory to other medications showed a marked improvement in symptoms with this levetiracetam treatment (Kyomen et al., 2007). An open-label prospective study found reductions in the NPI scores, but importantly also found significant reductions in MMSE scores and had patients with side effects including lethargy and paradoxically increased agitation (Weiner et al., 2005).

Anxiolytics

Benzodiazepines. Benzodiazepines are a commonly prescribed medication class for BPSD. A number of controlled studies have shown that benzodiazepines decrease agitated behaviors compared with placebo to the same extent as typical antipsychotics during short-term use (Chesrow et al., 1965; Kirven and Montero, 1973; Covington, 1975; Coccaro et al., 1990). There has been one study comparing intramuscular olanzapine, lorazepam, and placebo for the acute treatment of agitation in dementia. Both olanzapine (2.5 or 5 mg) and lorazepam (1 mg) produced significant acute reductions in agitation when compared to placebo. Side effects were similar between both active treatments and placebo (Meehan et al., 2002).

Short-acting benzodiazepines such as oxazepam or lorazepam that do not accumulate are preferred, and are most effective if used for short periods at low doses (e.g., lorazepam 0.5–2.0 mg/day). Lorazepam may be especially useful as a premedication for infrequent periodic episodic symptoms or where agitation or distress can be anticipated (e.g., minor surgical procedures or dental visits).

Side effects are common, and most often include excessive sedation (drowsiness), ataxia, amnesia, and confusion. The risk of falls with benzodiazepines is similar for short-acting when compared to long half-life medications with the greatest risk of falls associated with recent initiation of treatment (Cumming and Couteur, 2003). After patients have been maintained on benzodiazepines for more than 4–6 weeks, a gradual taper is advised prior to discontinuation to avoid withdrawal symptoms.

Buspirone. Buspirone is a serotonin 5-HT1a partial agonist that has been found to be helpful in agitated dementia patients in case reports and open-label studies (Herrmann and Eryavec, 1993; Levy et al., 1994). A small double-blind trial found that buspirone was associated with decreases in agitation and tension when compared to haloperidol (Cantillon et al., 1996). However, a placebo-controlled crossover study of buspirone (at doses of 30 mg/day), trazodone, or placebo found that buspirone was well tolerated, but had limited effects on agitation (Lawlor et al., 1994).
Miscellaneous drug classes

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).

Adrenergic blockers

There have been two uncontrolled studies of β-blockers in dementia that found some benefit (Petrie and Ban, 1981; Weiler et al., 1988). One small randomized trial of propranolol for agitation in nursing home residents with dementia found significant benefits for propranolol when compared to placebo (Peskind et al., 2005). A recent placebo-controlled trial of the alpha adrenergic antagonist prazosin (1–6 mg daily) for agitation or aggression in Alzheimer’s dementia found significant benefits in favor of the drug (Wang et al., 2009).

Selegiline. Selegiline, at low doses, is an irreversible inhibitor of monoamine oxidase B. 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. Although some small, open-label studies have shown beneficial effects on BPSD (Goad et al., 1991; Schneider et al., 1991), two large and placebo-controlled studies showed no effect of selegiline in patients with dementia (Freedman et al., 1998; Burke et al., 1993). 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).

Melatonin. Melatonin has been proposed as a treatment for agitation and sleep disturbances in dementia due to the known disruptions in melatonin that accompany dementia. There is limited evidence for melatonin in treating cognitive symptoms of dementia although melatonin may have modest effects on behavioral symptoms of dementia (Jansen et al., 2006).

Cannabinoids. Case-reports (Passmore and Passmore, 2008) and open-label studies (Walther et al., 2006) have suggested that cannabinoid medications may be beneficial in the treatment of agitation in dementia. A systematic review, however, concluded that the results of the only randomized controlled trial available could not be validated and that there was no evidence to support the efficacy of cannabinoids in the treatment of BPSD (Krishnan et al., 2009).

Treatment of sleep disturbances in dementia. No intervention studies exist on the use of sedative hypnotics for the treatment of sleep disturbances in AD (Salami et al., 2011), but in general, agents with short-to-intermediate half-lives and few active metabolites are 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 is recommended.
Antipsychotics have not been examined in the treatment of sleep specifically, but evidence from trials targeting behavioral symptoms suggests that sedative side effects of the atypicals may have a secondary effect on sleep (Salami et al., 2011). Given the associated risks in the elderly, their routine use in the treatment of sleep disturbance is not recommended, but could be considered in the context of psychotic symptoms or other BPSD requiring treatment. Similarly, evidence for the use of sedating antidepressants such as trazodone and mirtazapine is very limited, but these may be an option when sleep disturbance is co-morbid with depressive symptoms (Salami et al., 2011).

Acetylcholinesterase inhibitors have shown beneficial effects on sleep architecture (Moraes et al., 2008; Mizuno et al., 2004), but results from placebo-controlled studies on their use in the treatment in sleep disturbances have been mixed (Ancoli-Israeli et al., 2005; Markowitz et al., 2003; Moraes et al., 2008).

Melatonin has been proposed as a treatment option for sleep disturbances in dementia, but of four placebo-controlled clinical trials, three failed to find a significant effect. Two studies have reported that it may be more efficacious when combined with bright light therapy (Salami et al., 2010).

**Pain management in dementia.** It has been proposed that pain, common in people with dementia but often under recognized, may contribute to behavioral disturbances and may be an important target in the treatment of BPSD (Corbett et al., 2012; Husebo et al., 2011). More controlled trials are needed, but the most recent results suggest that it may be beneficial to adequately manage pain in patients with agitation and either obvious signs of discomfort or commonly painful comorbid medical conditions. A large cluster randomized controlled trial on the use of analgesics in dementia supported the efficacy of treating pain in reducing agitation, with a statistically significant improvement in agitation and aggression in patients receiving a stepwise pain treatment protocol including opioids (Husebo et al., 2011). A follow-up analysis reported that verbal agitation and physically non-aggressive behaviors, including restlessness and pacing, showed the greatest response (Husebo et al., 2013).

Other studies on the use of analgesics in the treatment of BPSD are few and have been equivocal. In a study aimed at addressing unmet needs employing both a non-pharmacological treatment program and analgesics in nursing home patients, there was an improvement in discomfort but not in behavioral symptoms (Kovach et al., 2006). In a small placebo-controlled trial, acetaminophen was not effective in reducing agitation but some improvement in social interaction was noted (Chibnall et al., 2005), while a statistically significant reduction in agitation was observed in only a subset of patients over 85 years old in a crossover trial with opioid analgesics (Manfredi et al., 2003).

**Electroconvulsive therapy for BPSD and depression**

Electroconvulsive therapy (ECT) may be an option in the management of severe depression complicating dementia. The use of ECT in individuals with dementia is limited due to the frequent occurrence of delirium following treatment. 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 treatment.

Case reports and retrospective studies suggest that ECT is effective in individuals with dementia and depression (Price and McAllister, 1989; Rao and Lyketsos, 2000; Liang et al., 1988). Case series also suggest that ECT may be a useful treatment for refractory cases of BPSD (Carlyle et al., 1991; Grant and Mohan, 2001). Capacity for informed consent for ECT in a dementia patient is difficult, and it is advisable to obtain the consent of a substitute decision maker.

**Special populations**

**Dementia with Lewy bodies and Parkinson’s disease dementia**

Dementia with Lewy bodies can be a relatively common clinical problem that has been observed in approximately 15% of dementia patients. Dementia also affects up to 25% of individuals with Parkinson’s disease (Aarsland et al., 2005). Visual hallucinations and other psychotic symptoms can be present early in the course of the disease. Severe and sometimes fatal sensitivity to conventional neuroleptics is a feature of dementia with Lewy bodies (McKeith et al., 2005), and patients with Parkinson’s disease dementia are also sensitive to neuroleptic medications.

Currently the best-supported evidence for treating behavioral symptoms associated with dementia with Lewy bodies is for cholinesterase inhibitors. Randomized controlled-trial evidence for rivastigmine in dementia with Lewy bodies (McKeith et al., 2000) has demonstrated improvement in BPSD symptoms with treatment. One study of rivastigmine for behavioral symptoms in Parkinson’s disease also found benefit on BPSD symptoms (Emre et al., 2004). In contrast, donepezil was not shown to be effective for BPSD in Parkinson’s disease dementia (Ravina et al., 2005).

There is limited information on the efficacy of atypical antipsychotics for dementia with Lewy bodies. Reports on the use of risperidone in patients with dementia with Lewy bodies have been mixed (Lee et al., 1994; Allen et al., 1995; McKeith et al., 1995). Post hoc analysis of individuals with dementia with Lewy bodies who were enrolled in a larger trial of olanzapine for BPSD found that 5 mg and 10 mg of olanzapine were more effective than placebo in reducing BPSD symptoms without worsening of motor symptoms (Cummings et al., 2002).

A retrospective chart review study of quetiapine in patients with Parkinson’s disease dementia or dementia with Lewy bodies found that the majority of individuals had reductions in psychosis during treatment, although motor worsening was observed in a third of patients (Fernandez et al., 2002). However, a small placebo-controlled trial of quetiapine for psychosis in dementia associated with Parkinsonism did not find any benefit of quetiapine over placebo (Kurlan et al., 2007). Clozapine currently is the best supported treatment for psychosis secondary to dopaminergic therapy in Parkinson’s disease (Pollak et al., 2004; Parkinson Study Group, 1999).

For severe BPSD, low doses of the newer antipsychotics such as quetiapine (6.25 mg), olanzapine (2.5 mg), or clozapine (6.25 mg) could be used, but patients must be monitored closely for treatment-emergent EPS and other adverse effects.
Frontotemporal dementia

Frontotemporal dementia (FTD) also has important differences in terms of symptom presentation and management when compared to Alzheimer’s disease. Individuals with FTD tend to have an earlier onset of illness and more pronounced behavioral symptoms or language impairment early in the course of illness when compared to Alzheimer’s disease (McKhann et al., 2001). Behaviors frequently observed in FTD include personality changes early in the course of illness, loss of social awareness and self-care, abnormal eating, and rigidity or repetitive and stereotyped interests and behaviors (Bozeat et al., 2000).

There have been relatively few high-quality studies examining pharmacological interventions for frontotemporal dementia. Serotonergic antidepressants are currently the best supported treatments for FTD (Kaye et al., 2010; Huey et al., 2006; Freedman, 2007). The only medication to demonstrate benefit in any placebo-controlled trial is trazodone (Lebert et al., 2004). Other antidepressants that have demonstrated benefit in uncontrolled studies have included fluoxetine, and sertraline with mixed results reported for two studies of paroxetine. Atypical antipsychotics including aripiprazole, olanzapine, and quetiapine have also demonstrated some benefits in case reports and open-label studies. The use of cholinesterase inhibitors and memantine in FTD is uncertain at the present time. Some studies have reported improvement in cognitive symptoms of FTD with cholinesterase inhibitors, although there may also be behavioral worsening. An open-label study of memantine for FTD suggested cognitive and behavioral benefits, although further studies are required (Boxer et al., 2009).

Treatments for inappropriate sexual behaviors

Inappropriate sexual behaviors may be observed in dementia. An important distinction must be made between normal sexual behaviors performed in an abnormal context, which may be related to disinhibition and impaired judgment, and hypersexual behaviors that may indicate an abnormal sexual drive (Ozkan et al., 2008). There are no randomized controlled trials of pharmacotherapies for inappropriate sexual behaviors. There is some evidence from open-label trials and case reports to support the use of gabapentin, carbamazepine, trazodone, paroxetine, citalopram, and cimetidine (Ozkan et al., 2008). Antiandrogens including medroxyprogesterone, cyproterone acetate, and finasteride may reduce inappropriate hypersexual behavior in men with dementia, but consideration should be given to the ethical concerns associated with their use in this context (Joller et al., 2013).

Treatment of apathy

Despite being widely recognized as one of the most prevalent and persistent behavioral symptoms of AD and other forms of dementia, studies of effective pharmacologic treatment options for apathy are relatively few. Evidence has been largely derived from trials investigating treatment of behavioral disturbances in general and rarely designed to assess apathy specifically.

Cholinesterase inhibitors are currently the best supported treatment option. Several open-label trials and one placebo-controlled trial demonstrated an improvement in neuropsychiatric symptoms including apathy in patients with AD treated with donepezil while only one study, in patients with AD or mixed dementia residing in nursing homes, found no benefit (Berman et al., 2012; Tariot et al., 2001). Galantamine was likewise effective in improving apathy in large
trial including patients with vascular and mixed dementia, and has been associated with a positive effect on apathy and fewer new behavioral symptoms in patients with mild to moderate AD (Cummings et al., 2004; Erkinjuntti et al., 2002; Herrmann et al., 2005). Two small studies of rivastigmine have supported its use for apathy and other behavioral symptoms in DLB, while open-label and observational studies have also demonstrated a benefit for treating apathy in AD (Berman et al., 2012).

Although evidence linking dysfunction in dopaminergic transmission with symptoms of apathy has suggested a potential role for psychostimulants, evidence for their routine use remains very limited (Herrmann et al., 2008; Berman et al., 2010). Only methylphenidate has been studied in placebo-controlled trials in patients with dementia. A small trial in AD patients showed an improvement as measured by the Apathy Evaluation Scale (AES), the best validated scale for measuring apathy in dementia (Herrmann et al., 2008). In a recent trial of patients with AD selected for clinically significant apathy, methylphenidate was associated with a modest but significant reduction in the NPI apathy score and a larger clinical impact with 21% of methylphenidate treated patients versus 3% of placebo-treated considered to have moderate to markedly improved (Rosenberg et al., 2013).

Evidence for other pharmacotherapy options is sparse, of poor quality, or has not yielded promising results. Of note, antidepressant medications including selective serotonin reuptake inhibitors and trazodone have demonstrated no benefit in the treatment of apathy (Berman et al., 2010). Similarly, studies of typical antipsychotics have been largely negative, and while retrospective analyses and one open-label trial have suggested atypical antipsychotics may be effective, this has not been confirmed in placebo-controlled trials (Berman et al., 2010).

References and recommended reading

General principles


The IPA Complete Guides to BPSD – Specialists Guide
Module 6: Pharmacological management


**Antipsychotics**


**Antidepressants**


**Cognitive enhancers**


McShane, R., Areosa Sastre, A., Minakaran, N. Memantine for dementia. *Cochrane Database of Systematic Reviews* 2006.


**Anticonvulsants**


### Anxiolytics


**Miscellaneous drug classes**


### Treatment of sleep disturbances in dementia


Pain management in dementia


Electroconvulsive therapy for BPSD and depression


Dementia with Lewy bodies and Parkinson’s disease dementia


**Frontotemporal dementia**


**Treatments for inappropriate sexual behavior**


**Treatment of apathy**


MODULE 7
Cross-cultural and transnational considerations

The IPA Complete Guides to Behavioral and Psychological Symptoms of Dementia

Specialists Guide

Specialists • Primary Care Physicians • Nurses
# MODULE 7: Cross-cultural and transnational considerations

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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 the level of tolerance for these symptoms within that culture.

- A 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 people with dementia.

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. In addition, studies examining neuropsychiatric symptoms in mild cognitive impairment (MCI) have emerged. This research will allow further investigations into the course of neuropsychiatric symptoms in the development of dementia.

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. As Shah pointed out, comparisons among different studies are problematic, because different studies have used different samples and settings, diagnostic groups, measurement instruments, methods of data collection, and methodology (Shah, et al., 2005).
In the following section, cultural factors critical to our understanding of the prevalence and presentation of BPSD and neuropsychiatric symptoms in MCI, and its assessment and management will be reviewed. Included in this is a comparison of BPSD in people of African descent residing in the United States, Jamaica and Nigeria. Further, the impact of research methodology on our understanding of these areas will be evaluated. Lastly, cross-cultural perspectives pertaining to BPSD in Turkey, India, Argentina, Brazil, Nigeria, Iran, Mexico, Japan, China, Hong Kong SAR, Taiwan, South Korea and minority elders in the United States 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. This lessened life span may influence:

- The development of BPSD
- 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 comorbid conditions of schizophrenia, depression, and alcoholism may also vary in frequency across communities and could alter the presentation of BPSD in persons with dementia. The 10/66 Dementia Research Group found that there were regional differences for individual behaviors with high rates of agitation, wandering, and sleep disturbance among Indian participants, and high rates of vocalization among Latin-American people with dementia. Overall, numbers of reported BPSD were highest in India, intermediate in Latin America, and lowest in China (10/66 Dementia Research Group, 2004). Culture-related factors may also influence the prevalence and presentation of BPSD. In some countries, caregivers deny BPSD to avoid the stigma of mental illness.

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. Argentines 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 treatment 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.
As illustrated in Table 7.1, population-based prevalence of BPSD in persons with dementia was dissimilar in the studies conducted in the United States (Lyketsos et al., 2002), United Kingdom (Savva et al., 2009), Spain (Fernández-Martínez et al., 2008), Brazil (Tatsch et al., 2006), China (Xie et al., 2004), Japan (Ikeda et al., 2004), and Nigeria (Baiyewu et al., 2003). Probably the most remarkable difference was the frequency of apathetic symptoms in China and Nigeria compared to other countries. This difference may be explained by the fact that apathy is generally under-recognized, especially in the elderly who have limited roles in society.

**BPSD in people of African descent living in Nigeria, Jamaica and the United States.** One of the major transcultural studies of dementia involved a comparison of 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, United States) (Hendrie et al., 1996). Differences in the prevalence and levels of tolerance of BPSD in each have been described. Ibadan is a major Nigerian city of more than one million people; however, despite its
The urban setting, the Yoruba community functions much like a village. The Jamaican population lives in a poor suburb of Kingston, and the African American population lives in a moderate-size city of approximately one million people.

Data regarding the prevalence of BPSD in the different communities were gathered from caregiver reports. The findings are presented in Table 7.2. It should be noted that these data are not corrected for age and severity of dementia among populations, and so direct comparisons among the groups are 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 result 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 United States 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.

Table 7.2: Prevalence (by percent) of selected BPSD and functional deficits in the United States, Jamaica, and Nigeria. Reprinted with permission from Hendrie et al., 1996.

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<td>Hallucinations</td>
<td>4</td>
<td>22</td>
<td>4</td>
</tr>
</tbody>
</table>

*Reflects the clinician’s opinion about whether the change significantly affected caregiving. The percentage in this category may be lower than that for the other subcategories.
Neuropsychiatric symptoms in MCI. Table 7.3 summarizes the population-based prevalence of neuropsychiatric symptoms in individuals with MCI. The commonest symptoms in MCI are depression, nighttime behavior, apathy, anxiety, and irritability. However, symptoms such as delusions, hallucinations, euphoria, disinhibition, and aberrant motor behaviors are relatively infrequent in MCI. Generally there are no remarkable differences across studies in the United States (Lyketsos et al., 2002; Geda et al., 2008), Brazil (Tatsch et al., 2006), Hong Kong (Chan et al., 2010) and Australia (Brodaty et al., 2012).

Table 7.3: Population-based prevalence (%) of neuropsychiatric symptoms in persons with MCI

<table>
<thead>
<tr>
<th>Symptoms in NPI</th>
<th>US Lyketsos et al., 2002</th>
<th>US Geda et al., 2008</th>
<th>Brazil Tatsch et al., 2006</th>
<th>Hong Kong Chan et al., 2010</th>
<th>Australia Brodaty et al., 2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>Delusions</td>
<td>3.1</td>
<td>3.4</td>
<td>0.0</td>
<td>2.4</td>
<td>0.0</td>
</tr>
<tr>
<td>Hallucinations</td>
<td>1.3</td>
<td>0.6</td>
<td>0.0</td>
<td>0.9</td>
<td>0.3</td>
</tr>
<tr>
<td>Agitation/aggression</td>
<td>11.3</td>
<td>9.1</td>
<td>8.0</td>
<td>5.1</td>
<td>4.7</td>
</tr>
<tr>
<td>Depression/dysphoria</td>
<td>20.1</td>
<td>27.0</td>
<td>16.0</td>
<td>14.6</td>
<td>14.7</td>
</tr>
<tr>
<td>Anxiety</td>
<td>9.9</td>
<td>14.1</td>
<td>24.0</td>
<td>12.5</td>
<td>5.0</td>
</tr>
<tr>
<td>Euphoria/elation</td>
<td>0.6</td>
<td>1.3</td>
<td>0.0</td>
<td>0.6</td>
<td>1.6</td>
</tr>
<tr>
<td>Apathy/indifference</td>
<td>14.7</td>
<td>18.5</td>
<td>12.0</td>
<td>15.2</td>
<td>4.7</td>
</tr>
<tr>
<td>Disinhibition</td>
<td>3.1</td>
<td>4.7</td>
<td>0.0</td>
<td>1.8</td>
<td>2.5</td>
</tr>
<tr>
<td>Irritability/lability</td>
<td>14.7</td>
<td>19.4</td>
<td>12.0</td>
<td>8.0</td>
<td>6.3</td>
</tr>
<tr>
<td>Aberrant motor behavior</td>
<td>3.8</td>
<td>1.3</td>
<td>0.0</td>
<td>0.9</td>
<td>1.9</td>
</tr>
<tr>
<td>Nighttime behavior</td>
<td>13.8</td>
<td>18.3</td>
<td>24.0</td>
<td>16.1</td>
<td>7.9</td>
</tr>
<tr>
<td>Appetite/eating change</td>
<td>10.4</td>
<td>10.7</td>
<td>4.0</td>
<td>2.1</td>
<td>6.0</td>
</tr>
</tbody>
</table>

Approaches to assessment

Evaluation of behavioral disorders in older 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 dementia and BPSD are perceived as a consequence of aging. As a result, caregivers may not even seek assessment of the symptoms unless these symptoms are deemed severe. 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 the awareness of dementia is heightened, and caregivers are finding outlets to discuss dementia. In immigrant countries such as Australia, Canada, the United States, and the United Kingdom, dementia awareness in minority ethnic groups may be lower than the rest of the population. For example, Italian, Greek and Chinese Australians had poor dementia literacy in comparison with third-generation Australians, and there were also differences among the three ethnic groups (Low et al., 2010).

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, because there is a high expectation of a certain level of personal hygiene in India (Chandra, 1996). A study comparing frontotemporal dementia (FTD) in the United States, Greece, and Turkey found that the frontal variant of FTD was diagnosed at an earlier age and had reported earlier symptom onset in the United States than in Greece or Turkey. Furthermore, neuropsychological measures indicate that at diagnosis, FTD patients in the United States were less impaired than patients in Greece and Turkey. Patients with FTD in Greece and Turkey were diagnosed later in the disease, presumably because their behavioral symptoms were not easily detected by the medical system in these countries (Papatriantafyllou et al., 2009).

Rating scales are an important means in 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 element is probably a reasonable way to proceed within one culture or one defined population, because informants’ views about what constitute acceptable behavior or disruptive symptoms are likely to be somewhat similar. This similarity 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.

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 (HMSE) and the Cognitive Abilities Screening Instrument (CASI), have been used successfully in cross-cultural studies. The Rowland Universal Dementia Assessment Scale (RUDAS) is an Australian screening instrument designed to be language- and culture-fair with promising psychometric properties (Rowland et al., 2006); however, it needs further validation across a range of cultural and ethnic groups, in different settings (general practice, acute hospitals, community service providers), and in measuring change.

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 et al., 2000). The NPI has been used to assess BPSD in the United States, Taiwan, Japan, and Italy. More recently, the NPI has been used in patients with dementia from Yoruba, Nigeria, after being translated, back translated, and harmonized into Yoruba (Baiyewu et al., 2003).

In its pilot study, the 10/66 Dementia Research Group made an attempt to develop a one-stage screening procedure for dementia in the community (Prince et al., 2003). They interviewed 2,885 persons aged 60 and older in 25 centers in India, China and South East Asia, Latin America, 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 tasks 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 Dementia Research Group 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 (Prince et al., 2003).

When conducting 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.
Shah et al., (2005) reviewed the instruments for measuring BPSD across different cultures and found that most measurement instruments have mainly been developed with conventional translation and back-translation techniques and subsequent evaluation of psychometric properties. Many rating scales have been translated and validated in other languages as documented in Table 7.4, which was adapted from Shah et al., (2005). In addition, the BEHAVE-AD has been used in India (Shaji et al., 2003) and the Neuropsychiatric Inventory (NPI) has been used in a Yoruba version in Nigeria (Baiyewu et al., 2003) and translated to Italian (Binetti et al., 1998). There are French versions of the Cornell Scale for Depression in Dementia (CSDD) and the Dementia Mood Assessment Scale (DMAS) (Camus et al., 1995) and a Chinese version of the Rating Scale for Aggression in the Elderly (RAGE) (Lam et al., 1997).

### Table 7.4: Available language versions of BPSD measurement instruments

<table>
<thead>
<tr>
<th>Instruments</th>
<th>Chinese Authors</th>
<th>Japanese Authors</th>
<th>Korean Authors</th>
<th>Dutch Authors</th>
<th>Spanish Authors</th>
</tr>
</thead>
<tbody>
<tr>
<td>NPI (Cummings et al., 1994)</td>
<td>Fuh et al., 2001</td>
<td>Hirono et al., 1997</td>
<td>Choi et al., 2000</td>
<td>Kat et al., 2002</td>
<td>Boada et al., 2005</td>
</tr>
<tr>
<td>NPI-NH (Wood et al., 2000)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Revised Memory and Behavior Checklist (Teri et al., 1992)</td>
<td>Fuh et al., 1999</td>
<td></td>
<td></td>
<td>Harwood et al., 2001</td>
<td></td>
</tr>
<tr>
<td>Cornell Scale for Depression in Dementia (Alexopoulos et al., 1988)</td>
<td></td>
<td>Schreiner and Morimoto, 2002</td>
<td>Shah et al., 2004</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### 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 older people
• Concepts of dementia and deviant behavior
• Tolerance of BPSD in the community

In the study from Nigeria and Jamaica (Hendrie et al., 1996), data on the 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 7.5 summarizes these findings.

Table 7.5: Treatment of BPSD in Jamaica and Nigeria. Adapted with permission from Hendrie et al., 1996

<table>
<thead>
<tr>
<th>Recognized</th>
<th>Kingston, Jamaica</th>
<th>Ibadan, Nigeria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatment available</td>
<td>Yes</td>
<td>Partially</td>
</tr>
<tr>
<td>Treatment sought</td>
<td>Yes</td>
<td>Seldom</td>
</tr>
<tr>
<td>More troublesome symptoms</td>
<td>Agitation</td>
<td>Agitation</td>
</tr>
<tr>
<td></td>
<td>Wandering</td>
<td>Violence</td>
</tr>
<tr>
<td></td>
<td>Violence</td>
<td>Delusions</td>
</tr>
<tr>
<td></td>
<td>Sleeplessness</td>
<td>Hallucinations</td>
</tr>
<tr>
<td>Type of treatment</td>
<td>Pharmacotherapy and milieu therapy</td>
<td>Little direct treatment</td>
</tr>
</tbody>
</table>

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 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 American populations. In Nigeria, caregivers often do not report symptoms such as hallucinations and delusions in their relatives with dementia for fear of a diagnosis of mental illness—something that carries considerable stigma in Yoruba culture.

Nursing home care is available for patients with dementia, with and without severe BPSD, in many countries. However, most patients with dementia reside at home with their families. In the United States, Caucasians utilize more nursing home beds compared to African Americans. In Turkey, patients with dementia reside mostly in their homes, although care in a specialized unit is reserved for those patients with severe BPSD. In Ibadan, Nigeria, there are no nursing homes for older patients with dementia, and consequently, all patients with dementia are managed at home by family members. Individuals with dementia are only brought to the 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 United States. There is little non-physician, community-based support. Treatment for the behavioral aspects of BPSD is primarily with milieu therapy, although pharmacotherapy is also used.

**Research methodological considerations**

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

- It is important to note the comparability (or lack thereof) of the populations studied. Many studies are of convenience samples in nursing homes or outpatient clinics. Often, little information is provided about dementia severity, type of dementia, or methods of assessment and whatever information is provided might not be 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 through studies with small sample sizes. More data from large representative samples are needed for useful comparisons.

**BPSD in minority elders in the United States**

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 situation is quite troublesome, in light of the diverse aging population.

Nearly 44 million people age 65 or older resided in the United States in 2013, representing about 13.9% of the population (CIA World Factbook, 2013). By 2060, the population aged 65 years and over is projected to more than double to 92 million (United States Census Bureau, 2012). The “oldest old,” representing those people aged 85 and older, is the fastest growing segment of the elderly population. Representing approximately 5.7 million people in 2008 (2% of the U.S. population), it is projected that this group will increase to 18 million (4.3% US population) by 2060.

As the older population continues to grow, diseases such as dementia have a devastating impact on the older people and society. In 2012, 5.4 million Americans suffered from dementia (Alzheimer’s Association, 2012). The growing number of patients with dementia has both public health and economic consequences. Despite underreporting, Alzheimer’s disease is the sixth leading cause of death each year in the United States (Alzheimer’s Association, 2012). Additionally, the annual cost of AD to society is approximately $200 billion (Alzheimer’s Association, 2012).

As the United States witnesses an explosion of the elderly population, there will be a marked increase in the diversity of this population. This growth is of concern, because dementing disorders have been found to be high or higher in African Americans and Hispanics than in Caucasians (Tang et al., 1998). Hispanic Americans will be the fastest growing group and are
projected to increase from 17.8% of the US population in 2015 to 30.6% in 2060; African Americans from 13.2% in 2015 to 14.7% in 2060; Asian Americans from 5.3% in 2015 to 8.2% in 2060; and those reporting two or more races from 2.6% to 6.4% (US Census Bureau, 2012).

Yet, there is little scientific literature on dementia as it relates to ethnic minority elders. This lack is due mostly to the underrepresentation 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; Arean and Gallagher-Thompson, 1996; Hall, 1999; Sinclair et al., 2000). 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) (Sano, 2000).

**Prevalence and presentation of BPSD in minority elders**

Numerous studies have evaluated the prevalence and nature of BPSD in the United States (for example, see Cohen-Mansfield, 2009; Steinberg et al., 2008; Jeste and Finkel, 2000; Chen et al., 2000; Chung and Cummings, 2000). 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, studies evaluating BPSD across racial and ethnic groups in the United States are presented in this module in order to highlight potential racial and ethnic differences and illustrate specific methodological issues.

Racial differences in neuropsychiatric symptoms were examined in 240 dementia outpatients (78% women) attending the Brooklyn Alzheimer’s Disease Assistance Center of the State University of New York from 1992–1995 (Cohen & Magai, 1999). 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.

Depressive affect was noted to be significantly higher in Caucasians than in African Americans. These findings are consistent with data showing fewer depressive symptoms among black nursing home residents (Walker et al., 1995). Psychoses and activity disturbance were noted to be significantly higher in African Americans, 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 were found 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 of this study included a nonrandom relatively small convenience sample of heterogeneous dementia 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.

A second study explored the stage-specific prevalence of behavioral symptoms in a multiethnic community sample of 125 outpatients diagnosed with either probable (n = 108) or possible (n = 17) Alzheimer’s disease at the University of Washington Alzheimer’s Disease Research Center (ADRC) (Chen et al., 2000). The study population included 38 African Americans, 63 Asian Americans/Pacific Islanders, 17 Hispanics, and seven 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 Alzheimer’s disease and NINCDS/ADRDA. Behavioral symptoms were evaluated utilizing BEHAVE-AD. 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 African Americans, who reported a lower overall prevalence of behavioral symptoms compared to the other ethnic groups and specifically had significantly reduced depressive, anxiety, and sleep symptoms compared to Asians and Hispanics.

Apart from possible concerns of the validity of the BEHAVE-AD (or any other behavioral scale for that matter) in a multiethnic population, the main limitations of this study were the convenience sampling and small sample sizes of the ethnic groups represented, thus limiting investigation of ethnic differences.

Two studies by the same research group, one a nursing home sample and the other a community sample post-discharge from a geriatric psychiatry unit, assessed for the presence and characteristics of agitation in African American and Caucasian patients with DSM-III dementia (Mintzer et al., 1996). 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 nonaggressive 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)

An evaluation of 104 agitated patients with dementia was conducted in the nursing home study. The skilled-nursing-home patients were recruited from 12 centers as part of a multicenter 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, who had a significantly
higher prevalence of aggressive behavior than Caucasians. Caucasians had a slightly higher prevalence of physically nonaggressive behaviors and verbally agitated behaviors compared with African Americans, but the differences were not statistically significant.

The community sample of 110 agitated patients with dementia post-discharge from a geriatric psychiatry unit had 86 Caucasians and 24 African Americans. The study population included 40 men. In the home setting, Caucasians exhibited significantly more verbally agitated behaviors than African Americans, 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 nonaggressive behaviors were found between African Americans and Caucasians. Although African American patients had a higher prevalence of aggressive agitated behavior in nursing homes than did Caucasians, these differences were not elucidated in the community-based sample. Overall, the authors concluded that differences in agitated behavior appear to depend more on the setting than on the patient’s race.

The limitations of these two studies included the small sample sizes, lack of control for dementia type and severity, and the higher proportion of males in the African American group.

A cross-sectional, case control study carried out at the Neuropsychiatry Service outpatient clinic at the Johns Hopkins School of Medicine, studied the relationship between isolated hallucinosis and race in AD (Bassiony et al., 2002). The participants were 237 community-residing patients with probable AD according to NINCDS/ADRDA criteria. Nine patients with isolated hallucinosis were compared to a control group of 228 patients who had neither delusions nor hallucinations. There was a significant association between hallucinations and race in patients with AD. Before adjustment for other variables, being African American conferred a 5.5-fold increased risk for isolated hallucinosis compared to being Caucasian. After adjustment for multiple other variables, this risk increased further to 27.2-fold. The limitations with this study included the small sample size and outpatient setting.

**Assessment of dementia and BPSD.** The actual assessment of dementia must be made before BPSD can be appropriately assessed. As stated earlier, a major goal is to develop culturally accurate measures that can be utilized in all ethnic populations (Sano, 2000). Clinicians and researchers must be aware that in the United States, ethnic groups differ from each other by language, communication, and 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 than in Caucasians, even after correcting for years of education (Sano, 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 among countries but also within each country (Sano, 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, because many scales and assessments require information from the caregiver (Sano, 2000). Cultural differences have been noted in caregivers. For example, caregivers tend to be spouses for Caucasian patients, although for African American and Hispanic patients, caregivers tend to be children or
siblings. In the future, the effect of caregiver relationships on outcome measures will need to be explored. A systematic review and meta-analysis of ethnic differences in minority ethnic (ME) people with dementia in western countries found that minority ethnic people were more cognitively impaired and Hispanic people reported a longer duration of memory loss than non-ME people at the time of referral to diagnostic dementia services in the United States. These differences remained after controlling for premorbid level of education (Cooper et al., 2010).

**Approaches to management.** Methodologically rigorous data is lacking in the evaluation of cultural differences in the management of BPSD in the United States. 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). Differences in anti-dementia medication use between non-Hispanic white and minority community-dwelling Medicare beneficiaries with dementia were investigated using multivariate analysis for anti-dementia medication use by race/ethnicity for 1,120 beneficiaries with dementia from years 2001 through 2003 of the Medicare Current Beneficiary Survey (Zuckerman et al., 2008). After adjusting for demographics, socioeconomics, health care access and utilization, comorbidities, and service year, the authors found that anti-dementia medication use was approximately 30% higher among non-Hispanic whites compared to other racial/ethnic groups. For individual racial/ethnic groups, prevalence disparities remained significant for non-Hispanic blacks and non-Hispanic others but were attenuated for Hispanics. 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 (Madhusoodanan, 2001; Chung and Cummings, 2000). Data suggest that minorities utilize nursing home care services less than non-minorities (Espino and Lewis, 1998; Walker et al., 1995; Valle, 1994). For example, data suggest that African American elderly utilize nursing homes at 50%–75% the rate of Caucasians (Walker et al, 1995).

**BPSD in the Middle East**

**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. The total population of Turkey was more than 80 million in 2013, with life expectancy of 73 years (male = 71 years; female = 75 years). Those 65 years old and older represented 6.6% of the total population (CIA World Factbook, 2013).

The concept of dementia is generally not considered a medical problem by the elderly Turkish population. A population-based, cross-sectional study of 859 people without dementia, aged 70 years or older, living in an urban area in Istanbul found that dementia was considered normal by the majority of respondents. Age and education did not influence this attitude, although women were significantly less inclined to consider dementia and its associated problems as normal (Sahin et al., 2006). Dementia prevalence in Turkey has been examined in a series of studies. In Middle Anatolia, the overall prevalence of dementia in 3,100 people aged 55 years and older was 8.4%, ranging from 2.2% among those aged 55–59 years to 5.3% among those aged 60–64 years, and to 30.4% among those aged 75 or older. Vascular dementia was the most common type (51.1%), followed by Alzheimer’s dementia (48.8%). Significant risk factors for dementia
were being female, low education, age, living in a rural area, and a family history of dementia (Arslantas et al., 2009). In Istanbul, the prevalence of dementia in 1,019 people aged 70 years and older was 20% (Gurvit et al., 2008). A third study in the low socioeconomic region of Izmir found a dementia prevalence of 22.9% in 204 persons aged 65 years and older (Keskinoglu et al., 2006).

**Assessment and frequency of BPSD.** 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). The Istanbul University, Cerrahpasa Medical School, Department of Geriatric Psychiatry has a memory outpatient clinic associated with the 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 study on BPSD, presented at the 2002 World Psychiatric Association Congress in Yokohama, Japan, 190 patients with probable DSM-IV AD, admitted (consecutively) to the memory outpatient clinic, were assessed. The Turkish version of the MMSE for educated and uneducated patients was used (Gungun et al., 1999). Specific behavioral symptoms were systematically assessed by using the Behavioral Pathology in Alzheimer’s Disease Rating Scale (BEHAVE-AD) (Reisberg et al., 1987). The 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.

More recently 217 patients with AD were evaluated from 18 referral centers across Turkey using a web-based dementia data registry (Yener et al., 2009). The MMSE and the NPI were used to evaluate the global cognitive function, and assessment of neuropsychiatric symptoms, respectively. The highest NPI scores were seen in patients with severe AD. The mean composite scores for apathy, anxiety, and depression were the highest. The prevalence of any behavioral symptom was 86%. There was no difference in the behavioral domain between the groups or between the referral centers. Moderate correlation was found between the severity of AD and the total NPI score. The caregivers’ NPI distress scores varied among the regional referral centers.

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 underreport 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 by their spouses or the eldest daughter in their homes. They are only admitted to a specialist unit when BPSD are severe. No specialized geriatric psychiatry consultation services are available for elderly people in the institutional care system in Turkey (Cankurtaran et al., 2006).

**BPSD in Iran**

While the elderly population is growing in Iran, aged health care and in particular mental health care is still in its infancy. There is no systematic screening and care program for dementing persons and behavioral problems of dementia are not regarded within the health program of the elderly. There is a shortage of centers providing care for patients with dementia and their disturbing behaviors. In developing countries such as Iran, there is still no systematized aged care program for dementia and its psychiatric manifestations.

Currently, patients complaining about memory problems are seen individually by general neurologists and psychiatrists. While they follow standardized diagnostic criteria, such as DSM to detect cognitive disorders like dementia, most are less familiar with challenging behaviors occurring in various stages of dementia. In addition to that, there are no consistent tools and approaches to BPSD. For this reason, the characteristics and management of BPSD in dementing patients remain strongly unexplored in Iran.

There is little research investigating the epidemiology and care of BPSD in Iran. Those few research and clinical projects are typically conducted by specialized university affiliated centers. Additionally, the Iran Alzheimer Association's educative and care program for dementing patients and their families are limited to a few areas of the capital, Tehran.

In Iran, like other developing countries, family members, particularly the spouse, are the main caregivers for the person with dementia. Most care occurs in the family home. The problems worsen when they move the family member with dementia from home to home. Over recent years the traditional family pattern, in which extended family of the same generation live together in large simple houses, has changed. Care for disabled senior families is limited to a few family caregivers in a limited housing space.

Results of an interventional study examining the role of family education on family caregivers have been promising. In this study, an eight-week educative program for caregivers has influenced both general health of caregivers and neuropsychiatric symptoms of patients. The most challenging behavior was night time behaviors. Sociodemographic variables, such as income and residential status, predicted more behavioral problems and subsequent burden to the caregivers (Javadpour et al., 2009).

In an empirical study on 50 consecutive older people with dementia referred to the psychogeriatric clinic of Shiraz University of Medical Sciences, the most problematic behaviors as measured by the Neuropsychiatry Inventory (NPI) were night time behaviors (55.2%) and aberrant motor behavior (51.7%). Delusions (44.8%), hallucinations (27.6%) and agitation (27.6%) were also common problems (Javadpour et al., unpublished study). The prevalence and severity of symptoms was correlated to dementia severity and the level of activities of daily living.
BPSD in Asia

BPSD in India

India is the largest democratic and culturally diversified nation. Rapid demographic changes are taking place due to better education, health facilities and increases in life expectancy.

Historical background. Historically, India has been a rural, agrarian 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 situation significantly lessened the burden of care. Things have changed in recent years, and the joint-family system is under stress. The emerging pattern is the following:

- Multiple families of the same generation are no longer living together
- The substantial burden of caring for frail or sick elderly is 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 caregiving

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. Because 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 conditions (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 condition is considered part of the aging process rather than a disease during old age.

Demography of India. According to the 2011 Census, the total population of India as of March 1, 2011 was 1.21 billion. The percentage of elderly population (over 60 years of age) has gone up from 5.3% to 5.7% during the period 1971 to 1981 and 6.0% to 8.0% respectively during the period 1991 to 2011. Male-Female differences in the age distribution of population are negligible except in the over 60 age-group and the 65+ age-group, where the percentage of female is 0.7% more than male. India is a “Graying Nation” by the United Nations standards (i.e., > 7% of total population). Currently the elderly population is greater than 90 million and this is expected to double by the year 2031. Two-thirds of the elderly population live in rural areas.

Economic conditions and social security for older people. The Indian aged population is currently the second largest in the world after China. The socio-economic condition of this group is a cause of concern, as most of them end up living below the poverty line due to inefficient and inadequate social security (Rajan, 2004). Social security schemes are available mainly for those retiring from the organized sector. Nearly 90% retiring from the non-organized sector with low wages, job insecurity and with lack of legal rights have no financial security. National Old Age Pension schemes provide nominal monthly pension of approximately
150–250 (US$3–5) to destitute persons above age of 65. Nearly 70% of all elderly are economically dependent on others, usually their children. Even those with pensions find their economic status lowered after retirement. Public investment in health care provision has not kept pace with population growth and the demand for basic health care (Prakash, 1999).

**Impact on family.** For generations, elderly people have been cared for by the traditional joint family system under which extended members of family live together—parents, children, children’s spouses and their offspring. Usually the oldest male member is the head in this system that would look after the elderly. With urbanization and economic development, India has witnessed a breakup of traditional joint family into more nuclear-like families (Sinha, 1993).

**Globalization and marginalization.** Globalization and economic development over the last three decades has had negative impact on the well-being and welfare of the elderly. Migration of younger generations from rural to urban areas and trans-national migration has resulted in elderly being left to fend for themselves. With empowerment of women, more women are entering the work force, tending to reduce both their availability of care giving and willingness to take on this additional role. In India, Venkoba Rao has coined an acronym to describe this growing social phenomena P.I.C.A. (Parents in India, Children Abroad). Consumerism has permeated and changed the fabric of contemporary Indian society. As a result, this group is marginalized further with great risk for neglect, abuse and exploitation (Pais, 2006).

**Impact of “Graying Nation” on health issues.** Decline in mortality rate in the elderly population has created a high incidence of morbidity. A key finding from the Global Burden of Disease (GBD) report is that chronic non-communicable diseases are rapidly becoming the dominant causes of ill-health (WHO, 2008). Co-morbidity such as hypertension, strokes, metabolic disorders, dyslipidemia, chronic obstructive pulmonary disease and arthritis, along with usual age-related cataracts and hearing loss is on the rise in India. The GBD report indicates that dementia is one of the main causes of disability in later life. The World Alzheimer’s Report (2009) highlights the importance of co-morbidity in the causation of disability and dependence.

**Dementia prevalence, costs of care and services.** The Alzheimer’s and Related Disorders Society of India (ARDSI) produced *The Dementia India Report 2010* in which it estimated that in 2010 there were 3.69 million people with dementia in India and that this number was projected to increase to 14.32 million by 2050 (ARDSI, 2010). It was estimated the total societal costs of dementia for India would range between US$9.4 billion to US$13.7 billion, depending on the quantum of informal care (1.6 hours per day or 3.7 hours per day respectively). Direct costs were estimated to be US$6.1 billion (Wimo et al., 2010). India has few dementia specific facilities, with only ten dementia day care centers, six dementia-specific residential care facilities, six domiciliary care services and 100 memory clinics (ARDSI, 2010).

**BPSD and burden of care.** The 10/66 Dementia Research Group studied the care arrangements for dementia patients. Information on 87 patients from India showed that most caregivers were female children of the people with dementia, living with the people with dementia in extended family households. More than half of households included children. However, despite the traditional apparatus of family care, levels of caregiver strain were at least as high as in the developed world. Many family members had cut back on work hours to be caregivers, but they 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 (The 10/66 Research Group, 2004).

**Nature and prevalence of BPSD.** Based on reports from centers engaged in dementia research, the prevalence of BPSD in India may be higher than the prevalence of BPSD found in other parts of the world. The 10/66 study examined BPSD in four centers in India (Goa, Chennai, Bangalore, and Thrissur) and in 14 centers in Latin America, three Chinese centers, and one in Africa (10/66 Dementia Research Group, 2004). Overall, the 87 Indian people with dementia were rated as having the highest rates of BPSD. Wandering, agitation, and sleep disturbances were particularly common in India.

The Thrissur Center of the 10/66 Dementia Research Group assessed BPSD in a sample of 29 patients meeting the DSM-IV diagnosis of dementia, 14 with Alzheimer’s disease, ten with vascular dementia, four with Lewy body dementia (DLB), and one ‘other dementia’ (Shaji et al., 2009). BPSD was measured with the BEHAVE-AD (see Table 7.6 for details). Patients with AD and DLB together had significantly higher total scores on BEHAVE-AD than did patients with vascular dementia; in particular, activity disturbances and delusional thinking were more common in AD and DLB.

BPSD symptoms cause severe stress on the coresident caregivers, who receive no support or guidance from the existing health care delivery system. In a qualitative study from Thrissur (Shaji et al., 2003), caregivers described BPSD and incontinence as the most distressing and difficult-to-manage symptoms. Dementia caregivers from Goa and Chennai spent significantly longer time providing care than did caregivers of depressed persons and controls (Dias et al., 2004). Emotional and economic strain was notably higher in the dementia caregivers.

### Table 7.6: BPSD in Thrissur district, Kerala, India (adapted from Shaji et al., 2009)

<table>
<thead>
<tr>
<th>BEHAVE–AD Items</th>
<th>People with dementia N = 29 (by percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>One or more BPSD</td>
<td>97</td>
</tr>
<tr>
<td>Paranoid and delusional ideation</td>
<td>66</td>
</tr>
<tr>
<td>Hallucinations</td>
<td>41</td>
</tr>
<tr>
<td>Activity disturbances</td>
<td>66</td>
</tr>
<tr>
<td>Aggressiveness</td>
<td>52</td>
</tr>
<tr>
<td>Diurnal rhythm disturbances</td>
<td>45</td>
</tr>
<tr>
<td>Affective disturbances</td>
<td>45</td>
</tr>
<tr>
<td>Anxiety and phobias</td>
<td>24</td>
</tr>
</tbody>
</table>
**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 relatives as deliberate misbehavior by a 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 diagnoses and treatment. There are no support groups to help family members, and consequently, both patients 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, the interventions could provide an important ingredient of community-based dementia care services in developing countries. Informing and educating 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 multicenter 10/66 Dementia Research Group has developed brief community-based caregiver education and training interventions administered by multipurpose health workers (MPHWs) (Prince and Trebilco, 2005). 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 because primary care teams often do not venture outside of their clinics. The training package for MPHWs includes 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, is given due emphasis in this intervention. Because many caregivers have low literacy levels, special educational aids and teaching materials would be provided. Such educational material is 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 18 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 that focus on the management of BPSD are likely to come up in many general hospitals that are usually located in the urban areas. Primarily, this focus is due to increasing demand for such services from the educated sections of the society.
Barriers to dementia care in India. The following barriers to dementia care have been identified:

- Lack of awareness and low health seeking behavior due to social stigma, dependency, financial restraints and ageism
- Unlikely to accept he/she has dementia because the condition is seen as accelerated ageing process
- A diagnosis is unlikely to be believed or its impact understood
- Special needs of dementia patient are not understood or respected widely enough
- Old age homes neither a popular nor feasible option
- Bias, ageism and poor awareness within medical fraternity
- Inadequate and discriminatory financing of mental health services for the elderly
- Lack of policy initiatives and implementations
- Lack of funds for dementia services, research and training
- There is no psychogeriatric curriculum and training in the undergraduate and post graduate courses
- Acute national shortage of medical and social service professionals who have training and expertise in geriatric mental health care

Dementia care services in India. Services exclusively for people with dementia in India are mostly provided by registered non-profit organizations. They are funded primarily by donations and public contributions apart from the charges collected from those who utilize the services. ARDSI, Helpage India, Dignity Foundation, Nightingales Medical Trust, Dementia Society of Goa, Sangath and Silver Innings Foundation are some of the providers. Services include day care centers (10), residential care facilities (6), domiciliary care services (6), memory clinics (100), dementia help lines (10) and support groups (exact data not available).

The Ministry of Social Justice and Empowerment, which is the nodal Ministry for the purpose of the Welfare of the Elderly, created the Maintenance and Welfare of Parents and Senior Citizens Act 2007. It was enacted in December 2007 to ensure need based maintenance for parents and senior citizens and their welfare and provides for:

- Maintenance of parents/senior citizens by children/relatives made obligatory and justiciable through Tribunals
- Revocation of transfer of property by senior citizens in case of negligence by relatives
- Penal provision for abandonment of senior citizens
- Establishment of old age homes for indigent senior citizens
- Adequate medical facilities and security for senior citizens

The Act has to be brought into force by individual State Government. As of 2010, the Act had been notified by 22 States and all Union Territories.

The ARDSI Dementia India Report 2010 made the following policy recommendations:

- Make dementia a national priority
- Increase funding for dementia research
- Increase awareness about dementia
- Improve dementia identification and care skills
Develop community support
- Guarantee caregiver support packages
- Develop comprehensive dementia care models
- Develop new national policies and legislation for people with dementia

There are concerns that India is facing an impending public health crisis. Perhaps the only way to move forwards with limited resources is through the empowerment of older people. This can be achieved through “advocacy, research, involvement of voluntary agencies, training different levels of gerontological workers, catalyzing the community, awareness building, organizing older persons themselves and networking with international agencies” (Prakash, 1999).

**BPSD in China, Hong Kong SAR and Taiwan**

**Prevalence and presentation.** Alzheimer’s disease is the most common cause of dementia in China, 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. In the past few years, several studies have been conducted to examine the prevalence of neuropsychiatric symptoms in persons with AD and in individuals with MCI in clinic settings and community-dwelling populations in mainland China (Zhang et al., 2012), Hong Kong SAR (Chow et al., 2002; Chan et al., 2010b), and Taiwan (Liu et al., 1995, 1999; Tsai et al., 1997; Hwang et al., 2000, 1997, 1996; Chow et al., 2002). The prevalence findings are summarized in Tables 7.7 and 7.8.

**Table 7.7: Prevalence (%) of neuropsychiatric symptoms in persons with AD and in individuals with MCI in Chinese patients.**

<table>
<thead>
<tr>
<th>Symptoms in NPI</th>
<th>AD</th>
<th>MCI</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Beijing (n = 129)</td>
<td>Taipei (n = 86)</td>
</tr>
<tr>
<td>Research setting</td>
<td>clinic</td>
<td>clinic</td>
</tr>
<tr>
<td>Delusions</td>
<td>39.5</td>
<td>31.5</td>
</tr>
<tr>
<td>Hallucinations</td>
<td>31.0</td>
<td>24.7</td>
</tr>
<tr>
<td>Agitation/ aggression</td>
<td>55.0</td>
<td>46.1</td>
</tr>
<tr>
<td>Depression/ dysphoria</td>
<td>33.3</td>
<td>49.4</td>
</tr>
<tr>
<td>Anxiety</td>
<td>30.2</td>
<td>39.3</td>
</tr>
<tr>
<td>Euphoria/elation</td>
<td>4.7</td>
<td>7.8</td>
</tr>
<tr>
<td>Apathy/ indifference</td>
<td>86.0</td>
<td>47.2</td>
</tr>
<tr>
<td>Disinhibition</td>
<td>19.4</td>
<td>19.1</td>
</tr>
<tr>
<td>Irritability/lability</td>
<td>63.6</td>
<td>51.7</td>
</tr>
</tbody>
</table>
### Table 7.8: Prevalence of neuropsychiatric symptoms (%) in persons with dementia in Taiwan (Liu, 1999, 1995; Tsai, 1997; Hwang, 2000, 1997, 1996).

<table>
<thead>
<tr>
<th>BPSD</th>
<th>Study in Psychiatry (Tsai, 1997; Hwang, 2000; 1997; 1996) (%)</th>
<th>Study in Neurology (Liu, 1999) (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depressive symptoms</td>
<td></td>
<td>22.0</td>
</tr>
<tr>
<td>Major depression</td>
<td>—</td>
<td>5.0</td>
</tr>
<tr>
<td>Minor depression</td>
<td></td>
<td>11.3</td>
</tr>
<tr>
<td>Anxiety</td>
<td>—</td>
<td>35.3</td>
</tr>
<tr>
<td>Delusions</td>
<td>62.9</td>
<td>27.2</td>
</tr>
<tr>
<td>Delusion of theft</td>
<td>55.6</td>
<td>27.2</td>
</tr>
<tr>
<td>Persecutory delusion</td>
<td>24.1</td>
<td>28.0</td>
</tr>
<tr>
<td>Delusion of infidelity</td>
<td>15.8–16.7</td>
<td>3.4</td>
</tr>
<tr>
<td>Delusion of abandonment</td>
<td>9.3</td>
<td>2.2</td>
</tr>
<tr>
<td>Misidentification of someone in the house</td>
<td>22</td>
<td>2.2</td>
</tr>
<tr>
<td>Misidentification of people</td>
<td>11.1</td>
<td>3.4</td>
</tr>
<tr>
<td>Misidentification of TV</td>
<td>9.3</td>
<td>—</td>
</tr>
<tr>
<td>Misidentification of mirror image</td>
<td>7.4</td>
<td>—</td>
</tr>
<tr>
<td>Misidentification—house is not patient's home</td>
<td>16.7</td>
<td>16.5</td>
</tr>
<tr>
<td>Hallucination</td>
<td>25.9</td>
<td>—</td>
</tr>
<tr>
<td>Visual hallucination</td>
<td>14.8</td>
<td>19.5</td>
</tr>
<tr>
<td>Auditory hallucination</td>
<td>16.7</td>
<td>11.6</td>
</tr>
<tr>
<td>Tactile hallucination</td>
<td>—</td>
<td>0.7</td>
</tr>
<tr>
<td>Olfactory hallucination</td>
<td>—</td>
<td>0.7</td>
</tr>
<tr>
<td>Hyperphagia</td>
<td>30.8–36.0</td>
<td>—</td>
</tr>
<tr>
<td>Pica</td>
<td>7.7</td>
<td>—</td>
</tr>
<tr>
<td>Verbal aggression</td>
<td>—</td>
<td>21.4</td>
</tr>
</tbody>
</table>
### 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. In a recent study conducted in a memory clinic in Beijing (Zhang et al., 2011), the occurrence of BPSD increases with the severity of AD. Three clusters of neuropsychiatric symptoms were mainly presented as measured with NPI, including psychosis and hyperactivity, and frontal and mood symptoms. The cluster scores of psychosis and hyperactivity, and frontal symptoms were significantly greater in severe AD compared to mild and moderate AD, but the mood symptoms did not change dramatically among three groups. Stepwise regression analysis showed that the total score of NPI correlated with the score of memory domain as measured with ADAS-Cog, and ADL score.

### Approaches to management.

Awareness of dementia among the general public is generally low in China, but it is emerging as an important public health issue (Chiu, Yu and Lam, 2010). The Practice Guideline of Dementia recommended the algorithm proposed by QoLDEM group to manage people with dementia (Chiu and Chiu, 2006), including three major components:

- **Pharmacological management:** Cognitive enhancers have been proposed as the first-line drug for dementia. Psychotropics, specifically referred to antipsychotics, antidepressants, mood stabilizers, and benzodiazepines, may be used for neuropsychiatric symptoms upon clinical benefit-risk evaluation.

- **Non-pharmacological intervention:** Clinicians, caregivers, and nursing staff are encouraged to use non-pharmacological intervention as the first choice for the management of BPSD.

- **Caregiver support:** Caregiver support groups have been organized, serving as the basis for health education, caregiving consultation, and a platform for sharing caregiving experiences. Also Alzheimer Associations in mainland China, Hong Kong SAR, and Taiwan have contributed greatly to improve the caregivers’ coping skills to manage the behavioral symptoms of persons with dementia.

The past few years have seen an increased interest in examining the effectiveness of non-pharmacological management of BPSD in Chinese communities (e.g. individualized functional training program in treating affective symptoms in persons with dementia (Lam et al., 2010)). Researchers have also looked into the pharmacological strategies for BPSD in the Chinese. One interesting finding is that studies in Hong Kong did not detect significant increases in mortality.
or cerebrovascular events in persons with dementia who were on antipsychotic medications (Chan et al., 2010a; Chan et al., 2011). It warrants further investigation in this area in other ethnic groups.

**BPSD in South Korea**

**South Korea in 2013.** Korean people are ethnically homogenous. Total population is 50 million. All Koreans are covered by the Nation Health Insurance Scheme, implemented in 1977. Proportion of elderly people age 65 and over is 12.3%. The number of people with dementia is estimated at 540,000. The long-term care insurance scheme was implemented in 2008 to provide home care, community care, and residential care for disabled elderly people with dementia and stroke. Life expectancy at birth is 79.6 years (male 76.5 years, female 82.9 years). The literacy rate is 98%.

**Prevalence of BPSD in South Korea.** Two studies using dementia cohorts in a geriatric hospital and a nursing home are introduced. The first study (Suh, 2004) was conducted in a nursing home with a total of 257 people with AD (n = 133) or vascular dementia (VaD) (n = 124) using the Cohen-Mansfield Agitation Inventory (CMAI). Eighty-three percent of the subjects with dementia manifested one or more agitated behaviors at least once a week. Verbally agitated behaviors were the type of agitation in which the highest percentage of subjects with dementia were engaged (67.3%), followed by 61.5% in physically non-aggressive behaviors, 38.5% in physically-aggressive behaviors, and 26.8% in hiding/hoarding behaviors. The most frequent agitated behaviors were cursing or verbal aggression (37.7%), screaming (37.7%), complaining (36.2%), negativism (30.7%), repetitive sentences or questions (30.4%), general restlessness (30.4%), and pacing and/or aimless wandering (28%). The percentage of subjects with dementia manifesting the four syndromal factors according to CDR stages in AD and VaD were shown in Figure 7.1. Prevalence rates of physically aggressive behaviors and verbally agitated behaviors in both AD and VaD group showed a linear upward trend as one progressed from one CDR stage to the next. Verbally agitated behaviors in VaD group were higher than those in AD group in CDR stage 2 and stage 3. Prevalence rates of physically non-aggressive behaviors and hiding/hoarding behaviors were higher in AD group.

![Figure 7.1: Prevalence of agitated behaviors of the CMAI-K at each Clinical Dementia Rating Scale (CDR) stage in Alzheimer’s disease (AD) and vascular dementia (VaD)](image-url)
The second study (Suh and Park, 2001) was conducted in a geriatric hospital with a total of 112 patients with AD using the BEHAVE-AD. The most frequent BPSD were depressed mood (47.6%), day/night disturbance (41.9%), agitation (41.0%), purposeless activity (39.4%), verbal aggressiveness (38.1%), tearfulness (36.2%), and anxiety and fear of being left alone (35.2%).

**Awareness of dementia including BPSD.** Many Korean people often regard dementia as a normal part of aging. Since 2008, when the long-term care insurance scheme was implemented, awareness of the significance of dementia and BPSD has been greatly raised. Before 2008, when there was no public assistance for dementia care, caregivers, general practitioners and even psychiatrists and neurologists had not made a concerted effort to find symptoms and signs of dementia. Thanks to long-term care (LTC) insurance, caregivers can reduce the burden of caring for dementia if they officially report symptoms of dementia, including BPSD, and can get approval for long-term care. Even media, doctor organizations and Alzheimer’s associations continued campaigns to raise awareness of dementia. In 2009, the President of the Korean government declared a war against dementia.

**Assessment of dementia.** Rating scales have been translated into the Korean language and harmonized with the Korean population. Some rating scales for BPSD such as the CMAI, BEHAVE-AD and NPI have been validated and widely used in Korea. Further, the Korean versions of clinical assessment instruments such as 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), the Composite International Diagnostic Interview (CIDI), and the Diagnostic Interview Schedule (DIS) are also available.

It is widely accepted that the initial identification of likely cases of dementia is an important function of primary care. It is widely suggested that formal diagnosis should be done by specialists. Neurologists and psychiatrists were most frequently diagnosing and managing dementia. Primary care physicians, geriatricians and nurse practitioners were less likely to be involved in diagnosis. Memory clinics are providing assessment, diagnosis and management of dementia, while dementia care is mostly provided by social services and long-term care scheme.

**Management of dementia.** Initiation of anti-dementia drug prescription should be carried out mostly by dementia experts. There appear to be relatively long delays separating a patient’s initial diagnosis of dementia and the start of treatment. Slow initiation of treatment in newly diagnosed patients might be attributed to the pessimism about dementia as an incurable disease and to the unwillingness of patients and their families to receive treatment. All available anti-dementia drugs (i.e., donepezil, rivastigmine, galantamine, memantine) have been used as first-line drugs. Donepezil is always ranked as a first-line drug and most commonly prescribed. Vitamin E and ginkgo biloba are used for combination therapy.

The LTC insurance scheme provides dementia services at home, community and institutions with co-payment by care recipients. In addition, Korea has introduced small group homes of 6–10 residents, who are supported by staff around the clock, as an intermediate level of care between home and institutional care. Group home living provides an alternative to traditional institutionalization/residential care when there is a lack of informal or formal community support.
Challenges. It is expected that the LTC system can reduce the deficit in health insurance for health expenditure for the elderly. In Korea, 92% of long-term care beneficiaries suffer from chronic diseases, and 74.2% of them utilize medical services. In spite of entering into the LTC system, the need for disease management of these beneficiaries is not diminished. One of the challenges of the present health and LTC insurance program is how to meet the complex medical needs of those residing in LTC facilities or using community LTC services.

BPSD in Japan

In July 2013, Japan Ministry of Health, Labor, and Welfare announced the average life span of the Japanese in the year 2012 was 86.41 years for females and 79.94 years for males. The average life span of the Japanese female had been the longest in the world for 26 consecutive years until 2010, when it became second to Hong Kong in 2011, and then returned to the longest in 2012 by increasing 0.51 years compared with that of 2011. The average life span of Japanese males was ranked first in the world by increasing 0.50 years compared with that of the previous year.

In the years 1891–1898, the Japanese life span was only 44.3 years for females and 42.8 years for males, which became slightly shortened to 43.20 for females and 42.06 for males in 1921–1925 due to the Spanish influenza and loss of lives by the Kanto Earthquake in 1923. Before World War II, the average life span of the Japanese never exceeded 50 years. In 1947, the average life span of the Japanese was 53.96 for females and 50.06 for males, and it has shown rapid increase, especially in the period of 1954–1973, which coincided with rapid economic growth of Japan, reaching the longest life span, 83.18 years, which is expected to increase in the coming years.

Society aging. In the year 1936, the proportion of elderly people in Japan, age 65 years and above, was low (4.7%), and stable until the 1950s. Since then, it has shown a steep increase, exceeding 7% in 1970, 14% in 1995, and 20% in 2007. The Japanese total population was at its highest in 2007. The proportion of older people in the population, however, will keep increasing until the year 2050 when it is estimated to reach over 40% of the total population, following the second generation of the baby boomers (born in 1947–1949) attaining the age of 65. During the same period, the people in the productive age group (15–64 years old) will keep decreasing. At the present time, the productive age group is 65% of the total population, implying 2.5 people in the productive age group support one older person. In the near future, however, one person of productive age will support the life of one older person. Another feature of Japan is the significant increase in the ratio of the ‘old old’, 75 years or above. Now the ‘old old’ ratio is 10%, which will be increased to 22% by 2050 (Japanese Ministry of Health, Welfare & Labor, 2012).

Rapid transition from aging to aged society. When we compare the speed of the transition from an aging society (7% elderly) to an aged society (14% elderly), most European countries spent more than 50 years in this transition. France spent 115 years, United States 71 years, and Italy 61 years in transitioning from an aging society to aged society, while Japan transited in only 24 years (Takeda, 2004). Too rapid transition in a society will cause strains and frictions in social systems because the society itself will move forward before the social system becomes adapted to the change and people in the society become used to it. The Japanese Government is prepared for this type of social strain and in 2000 implemented Long-Term Care Insurance and the Adult Guardian Law.
BPSD. The Japanese Psychogeriatric Society collaborated in introducing the second edition of the IPA Educational Pack (2003) to Japanese professionals by producing a Japanese translation, which was published in 2005 (Fig. 7.2). The third edition, the Complete Guide to BPSD (2011) was also published in the Japanese language in 2013 (Fig. 7.3).

BPSD can be understood as the reflection of the friction between the person with dementia and other people caused by their incomplete recognition of the outside world. The key message is for clinicians to understand the background reason of various types of BPSD and try to resolve this difficult situation of the person with dementia and caregivers. Caregivers or family members should not think that BPSD is the problem of only the person with dementia, but we should think about how to resolve the situation caused by the friction between the person with dementia and the environment, paying more respect to the person’s autonomy. We should find ways to help people with dementia keep functioning in society by reducing BPSD.

Japan is a leader in the world in terms of society aging and we think Japan is expected to create a new society in which people with dementia can live happily and safely, paying more attention to their needs so that this can be achieved for as long as possible.

Management of BPSD. A recent survey conducted in Japan showed that many family doctors prescribe antipsychotics to dementia patients, but only 19% of them prescribe antipsychotics after informed consent from the family of the patients (Japanese Ministry of Health, Welfare & Labor, 2013). Some family doctors prescribe antipsychotics to patients with types of BPSD which are known to have a poor response to antipsychotics such as talkativeness, pica, overeating, wandering, or resistance to care. Considering these facts, the Japanese Government has issued the statement that easy use of antipsychotics to people with dementia should be discouraged. In the statement, family doctors are advised to try to manage BPSD by modulating
environmental factors or by non-pharmacological means before using antipsychotics. Antipsychotics use for people with BPSD should be minimized. The following should be observed by family doctors:

- No antipsychotics have been approved for the treatment of BPSD because no data are available about the usefulness of antipsychotics for BPSD in Japanese patients. On the contrary, there are data which show antipsychotic use may increase risk of falls and bone fractures in people with dementia.
- Use of antipsychotics should be restricted to moderate to severe BPSD, such as aggression, excitement, or psychotic features and when there is no other choice to control BPSD.
- After the initiation of antipsychotics, the clinicians are expected to evaluate the necessity of continued use by close observation and discontinue them when there is no further benefit.
- Use antipsychotics in combination with non-pharmacological interventions.
- Try to avoid polypharmacy.
- Avoid antipsychotics which have higher risk of extrapyramidal side effects or tardive dyskinesia.
- Explain to the family members in detail the possibility of adverse side effects, such as falls, orthostatic hypotension, over sedation in addition to the increased risk of sudden death and cerebrovascular events and obtain consent.
- When there are signs of adverse effects, such as gait disturbance, dysphagia, dysarthria, rigidity, tremor, orthostatic hypotension, oversedation, reduce the dose or stop the use of antipsychotics as soon as possible.

**Government policy to improve care for dementia patients.** In September 2012, the Japanese Government announced a five-year policy plan to promote dementia care, in which the shift from late management to early intervention and management was strongly recommended, based on the understanding that the previous policy was mainly focused on post event management and crisis management due to BPSD. The Government is now advocating that early intervention and even preventive measures are more important and cost-effective in dementia care. The Government policy recommended:

- Standard care path for dementia care should be formalized, and be used in reimbursement of medical and care costs for dementia.
- Special teams for early identification and intervention of dementia patients should be implemented.
- The number of medical centers should be increased where early diagnosis of dementia can be made to 500 centers by year 2017.
- The number of family doctors who see dementia patients should be increased to 50,000 by 2017.
- The number of specialists for dementia should be increased to 4,000 by year 2017.
- Every town or city should have the specialized team for dementia care support.
- The number of social workers specialized for dementia should be increased to 700 by 2017.
- Education to the public should be promoted to increase the number of citizen dementia care supporters to 5,000,000 by 2017.
Conclusions. We are born alike as babies and accumulate our own experience along our life. When we enter old age, we show a great variety of reactions depending on our psychological and social experiences. The biological variance is large enough in old age, but the psychological and social variance makes us even more different. We should keep in mind that older people show wide variance due to psychological and social factors in addition to biological factors.

Dementia is a disease in which social life capacity is impaired due to gradual impairment in memory or cognitive function. People with dementia gradually lose social function, which makes it difficult for them to maintain adequate relationships with other people in society. As dementia progresses, personal life capacity such as meal preparation, bathing and toileting, will also be lost. But the biological life capacity such as respiration, circulation and body temperature will be mostly maintained. In other words, loss of social function is the core symptom of dementia, and psychological and social factors should be considered when we are facing BPSD. People with dementia are so different, just like healthy old people, and we clinicians are expected to differentiate the BPSD of each patient.

BPSD in Latin America

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 Brazil, 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. In the 2009 World Alzheimer Report, it was estimated that there were 51.9 million people age 60 years and older living in Latin America (Alzheimer’s Disease International, 2009).

Studies by the 10/66 Dementia Research Group, including seven sites from five Latin American countries (Peru, Cuba, Dominican Republic, Mexico, and Venezuela), have shown that the prevalence of dementia in this region is perhaps the highest in the world at 9.5% of the population age 65 years and older, according to 10/66 estimates, and 4.2% using DSM-IV criteria, with the discrepancy due to underreporting of cognitive decline and social/occupational impairment by relatives (Ferri and Prince, 2009). The 10/66 Dementia Research Group reported on BPSD in 387 Latin American people with dementia and compared them with Chinese, Indian, and African participants. Latin American participants had intermediate rates of BPSD but the highest rate of vocal disturbances (37%) and depressive syndromes (51%), although phobic neuroses and manic/hypomanic psychoses were only found in Latin American countries (The 10/66 Dementia Research Group, 2004).

BPSD in Argentina

Argentina is populated by a mixture of different ethnic cultures; however, unlike other Latin American countries, most Argentineans (97%) 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 northern and western parts of Argentina are populated by a greater proportion of natives and mestizos living in rural areas; the center and the southeast are populated by European descendants, for the most part.
Argentina has one of the largest elderly populations in Latin America, with 11.3% of the population age 65 years and older (4.8 million) and a life expectancy at birth of 77 years (CIA World Fact Book, 2013). It is a highly urbanized society with 92% of the population living in cities, and about 15 million people living in the greater Buenos Aires region (CIA World Fact Book, 2013). The adult illiteracy rate is 2.8% for the population over 15 years old but higher in the elderly. 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 that cope not only with the patients’ language and culture but also to their educational levels.

It is estimated that there were nearly 322,000 people with dementia in Argentina in 2009 (Wimo et al., 2010). The total annual estimated cost was about US$4.6 billion per year if informal costs are just based on ADL support and more than US$7 billion each year if IADL support is included (Wimo et al., 2010). 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. Most senior citizens live at home with their families; approximately 15% are institutionalized in nursing homes. This arrangement may result partly from the tradition of extended families, but it also evolves from the high cost of nursing home care.

**Frequency of BPSD.** In Argentina, the Neuropsychiatric Inventory and the BEHAVE-AD are the most common tools used to assess BPSD. One study of BPSD in 72 patients with AD found a prevalence of 87.5% using the Neuropsychiatric Inventory NPI-Q (Pollero et al., 2004; Kaufer et al., 2000). The most frequent symptoms were apathy, irritability, depression, and anxiety. Symptoms were predominantly found in moderate and severe dementia apart from depression and anxiety that were more common in mild-moderate dementia. A study of 258 patients with dementia from a memory clinic in Buenos Aires reported that over 44% had psychotic symptoms and 59% had depressive symptoms at least weekly (Machnicki et al., 2009).

**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 caregivers. Aggressiveness, pacing, moaning, or shouting were among the items on the Functional Dementia Scale that were identified as independent predictors of caregiver burden. A more recent study found that behavioral, cognitive and functional factors contributed to caregiver burden in a memory clinic sample in Buenos Aires (Machnicki et al., 2009).

**Approaches to management.** Treatment depends on psychosocial and demographic factors; there are differences between the principal cities (such as Buenos Aires, Cordoba, Rosario, Mendoza) and the smaller cities or rural areas. For example, caregivers in the principal cities are more likely to be burdened by pacing or wandering than those in the provinces where most patients live in houses with room enough to pace and without the danger of becoming lost. 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 relatives and are likely to keep others from knowing the difficulty of their caregiving situation. They also rely on prayer and their faith to handle problems related to caregiver burden (Mangone, 2000).

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 residencies, and there are few specialists trained in dementia. In the past decade the role of memory clinics in dementia diagnosis has increased. These are mainly located in the private sector and are mostly run by neurologists (Bagnati et al., 2013).

There is evidence that admission to residential care in Buenos Aires is skewed towards social reasons with barriers for the admission of people with dementia (Lloyd-Sherlock and Redondo, 2009).

The pharmacological treatment approaches are similar to those in the United States. There are support groups (Association against Alzheimer’s disease and Related Disorders of Argentina—ALMA) to help family members with more than 20 located around the country.

BPSD in Mexico

Background. Mexican society is a mixture of different cultures. Most Mexicans (60%) are descendants of the Spanish and native fusions. However, within its vast territory, more than 60 different native languages are still spoken, each one with its own particular culture and beliefs.

Demographically, Mexico is rapidly changing into a country where the children and the young no longer dominate the age structure. The population of over 116 million has 8 million (6.9%) people age 65 years and over (CIA World Factbook, 2013). The growth of the older population is expected to increase almost threefold in the next 20 years, with its concomitant burden to the economy and service delivery for the aged. In 2009 it was estimated that there were more than 485,000 people with dementia in Mexico (Wimo et al., 2010) and, according to the 10/66 Dementia Research Group, the prevalence of dementia in people 65 years and older was 8.6% in urban areas and 8.5% in rural areas (Ferri and Prince, 2009). 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 who will develop dementia were the top priorities. The intent to develop a national action plan for dementia was announced in 2012 and is the first in the Spanish-speaking world.

BPSD prevalence and caregiver burden. In recent years several studies have quantified aspects of BPSD in Mexico. Data from the 10/66 project involving 180 cases diagnosed with dementia from a population-based cross-sectional study of 2,003 older adults living in rural and urban areas of low- to medium-income in Mexico used the abbreviated version of the Neuropsychiatric Inventory (NPI-Q) to measure BPSD. Depression (47.8%), sleep disorders (37.2%) and
irritability (34.4%) were the most prevalent and increased with dementia severity. Anxiety, depression and sleep disorders were associated with mild/moderate caregivers stress levels (Acosta-Castillo et al., 2012). Fewer BPSD were reported from rural areas (Rodriguez-Agudelo et al., 2011). A multicenter study from Mexico City reported that caregiver burden as measured by the Spanish Caregiver Burden Screen was associated with dysexecutive syndrome and sleep disorders as well as caregiver depression (Rosas-Carrasco et al., 2013).

**BPSD in Brazil**

According to United Nations (UN) estimates for 2005, Brazil was considered as belonging to the group of ten countries with the largest population of people aged 60 years or more, and estimates indicate that Brazil, in 2050, will be one of the six countries that have more than 10 million over 80 years old. Among developing nations, Brazil has the highest percentage increase of the elderly population worldwide, with the group above 60 years-old increasing by about 23 times from 1950 to 2050, while its population as a whole is expected to grow about 4.5 times during this period (UNO, 2002).

Since 2002, several research studies have described the prevalence of dementia in the population over 65 years old in Brazil. The first one reported that in older subjects living in Catanduva, in the state of São Paulo, dementia prevalence was 7.1% (Herrera Jr et al., 2002). In another study (Bottino et al., 2008), the estimated prevalence of dementia found in São Paulo city was 12.9% in the population over 60 years, figures equal to or higher than the prevalence rates of dementia found in developed countries (Lopes et al., 2007).

In parallel with the interest in dementia, the BPSD or neuropsychiatric symptoms in dementia have been studied more intensively in the last few years. On a PUBMED search using the keywords BPSD or neuropsychiatric symptoms, dementia and Brazil, 32 original articles and reviews were found since January1999 to June 2013.

**BPSD prevalence and measurement.** Following reports of BPSD prevalence in outpatient samples, the first account of these symptoms on a representative sample with Alzheimer’s disease (AD) or Cognitive Impaired Not Demented (CIND) was published by Tatsch et al. (2006). The authors reported that 60 patients with AD, 25 CIND, and 78 healthy elderly subjects were evaluated. Of this sample, 78.3% of patients with AD had one or more neuropsychiatric symptoms, with apathy (53.3%), depression (38.3%), sleep alterations (38.3%), and anxiety (25%) the most prevalent disturbances in AD subjects. In the CIND group, the most frequent neuropsychiatric symptoms were anxiety and sleep alterations (both with 24%) followed by depression (16%), while the total NPI scores were significantly different between the three groups. Apathy was the only symptom that was significantly different between the groups divided according to the CDR, being more frequent in subjects with moderate to severe dementia. The authors concluded that neuropsychiatric symptoms seem to be as common in patients living in a developing country as they are in dementing patients from the developed world, suggesting that cultural factors play a minor role in the emergence of these symptoms, at least in a country like Brazil (Tatsch et al., 2006).
Another significant contribution to the field was the publication from Camozzatto et al. (2008), which reported the psychometric properties of the Brazilian Portuguese version of the Neuropsychiatric Inventory (NPI), in a sample of 36 Alzheimer’s disease (AD) outpatients from southern Brazil. The Brazilian version of the NPI showed good inter-rater, test-retest reliability, and internal consistency. Apathy provided higher NPI scores of total severity and distress.

In another research line, Stella et al. (2009) presented an account of 50 patients with idiopathic Parkinson’s disease (PD) and their caregivers seen consecutively at the Movement Disorder Outpatient Clinic at the Hospital of State University of Campinas. The authors found that patients with PD and dementia presented the highest NPI scores, followed by patients with PD and depression. Caregivers’ burden was found to be proportional to the degree of patients’ symptomatology. Patients with dementia presented more severe motor impairment and lower functionality, with psychotic symptoms, agitation, aberrant motor behaviors and sleep disturbances higher in the dementia group.

**BPSD treatment.** Regarding BPSD treatment, interesting reports have investigated the efficacy of non-pharmacologic interventions to reduce the neuropsychiatric symptoms of AD patients and caregivers’ burden. For instance, a controlled trial to evaluate the effects of a motor intervention program on the neuropsychiatric symptoms was performed on community patients from two university centers specializing in physical exercise for the elderly (Stella et al., 2011). Thirty-two AD patients were divided in two groups: the motor intervention and the control groups. Aerobic exercises (flexibility, strength, and agility) and functional balance exercises were conducted over six months for 60 minutes, three times per week. Patients from the intervention presented a significant reduction in neuropsychiatric conditions when compared to controls. The burden and stress of caregivers responsible for patients who participated in the intervention significantly decreased when compared to caregivers responsible for controls. The authors concluded that aerobic exercise was associated with a reduction in the neuropsychiatric symptoms and contributed to attenuate the caregivers’ burden, but the researchers were not blinded to the patient’s intervention status, which constituted a limitation of the study.

In another paper, a multidisciplinary rehabilitation program on cognition, quality of life, and neuropsychiatric symptoms was applied to 25 patients with mild AD and their caregivers. They were included in a 12-week stimulation and psychoeducational program and compared to 16 AD patients in waiting lists. Group sessions were provided by a multi-professional team and included memory training, computer-assisted cognitive stimulation, expressive activities (painting, verbal expression, writing), physiotherapy, and physical training administered twice a week. Measurements of global cognitive function and performance on attention tasks indicated that patients in the experimental group remained stable, whereas controls displayed mild but significant worsening. The intervention was associated with reduced depressive symptoms for patients and caregivers and decreased neuropsychiatric symptoms in AD subjects (Viola et al., 2011).

Finally, forty dementia family caregivers were enrolled in a Cognitive-Behavioral Therapy (CBT) program intervention across eight weekly sessions (Fialho et al., 2012). At the end of the program, family caregivers reported fewer neuropsychiatric symptoms among patients and an
improvement in patients’ quality of life. In addition, caregivers changed their coping strategies, whereas a significant decrease was observed in their anxiety levels. These studies stressed the importance of considering structured non-pharmacological interventions for patients with dementia and their caregivers to reduce BPSD symptoms and caregivers burden.

Conclusions. The BPSD field in Brazil is moving forward, departing from the initial reports of prevalence of symptoms to more recent studies focusing on the neurobiology and non-pharmacological treatment of these symptoms. The education of clinicians to correctly identify and manage these symptoms is a fundamental task to improve the care of dementia patients with BPSD and their caregivers in Brazil.

BPSD in Africa

This section will mainly focus on BPSD in Nigeria. However in Africa there are high rates of HIV-associated dementia in HIV positive patients ranging from 14% in Malawi (Patel et al., 2010) to 31% in Uganda (Wong et al, 2007). Thus, patients with dementia are also likely to have a shorter life expectancy.

BPSD in Nigeria

Baiyewu et al. (2003) examined 40 people with dementia residing in Nigeria using the NPI and found that changes in eating behavior, mood, and irritability/lability were the most prevalent BPSD (see Table 7.1). There had been other studies on BPSD or other behavior symptoms in Nigeria using the NPI as well. Baiyewu et al. (2012) reported BPSD in subjects whose diagnosis remained stable as normal or CIND/MCI over a period of three years in the Indianapolis-Ibadan Community based dementia study. In that study, patients diagnosed with dementia, CIND/MCI and normal cognition in 2001, were administered the NPI at a mean period of 17 months after assessment. Those with diagnoses of MCI and normal were reassessed in 2004, and then those with stable diagnosis of CIND/MCI or normal cognition were included in analysis. Major findings were that frequency of depression was higher in CIND/MCI and dementia compared with normal cognition, but severity and distress impairment increased from normal cognition through CIND/MCI to dementia. Caregivers of patients with dementia rated depression, apathy and hallucination as more severe in dementia compare with MCI and normal cognition. Only hallucination was significantly more distressful in dementia compare with MCI and normal cognition. Hallucinations were recorded only in subjects with dementia.

Caregivers were predominantly females (about 70%) with an average age of 40, while participants with dementia were also predominantly females (about 80%) averaging 80 years old. Both MMSE and Blessed Dementia Scale correlated with NPI severity and distress. Although 62% of participants with normal cognition had behavior symptoms, these were neither severe nor distressful and probably due to physical illness conditions like blindness and arthritis. Authors opined that it is necessary to consider starting intervention for BPSD from the stage of CIND/MCI since it appears that significant symptoms exist at this stage (Baiyewu et al., 2012).

A related study by Ojagbemi et al. (2013), also using NPI, rated behavior symptoms in 50 idiopathic Parkinson’s disease patients and compared that with 50 age and gender matched controls who had a diagnosis of essential hypertension, but had controlled BP. Main findings
were that behavior symptoms were more prevalent, more severe and caregivers of Parkinson’s
disease patients expressed more distress than caregivers of patients with hypertension.
Delusions, hallucinations, agitation, apathy irritability and appetite change were significantly
more frequent. Irritability, appetite change and total severity NPI scores were significantly
more severe; while significant distress was recorded with delusions, hallucinations, agitation,
depression, apathy, appetite change and total NPI distress score. Mean age of Parkinson’s
disease patient was 65 years and about 75% of them had some schooling. Seventy four percent
of patients with Parkinson’s disease had at least one behavior symptom compared with 64% of
controls. Slightly more than half of the caregivers for Parkinson’s disease were males and were
about 40 years old; about 50% had university or college education.

As part of the Indianapolis-Ibadan dementia project, a caregiver support group led by a
physician and nurse was established and was very well received by 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.

Donepezil is now available in Nigeria, but it is very expensive, and it is difficult to convey to
families in which improvements are limited and might take months to achieve. Caregivers are
often looking for a permanent cure. It is not unusual for psychotropics and hypnotics to be used
inappropriately with unacceptable drowsiness and other side effects (Uwakwe, 2010).

There are now formal treatment modalities in some centers in Nigeria. At the University
College Hospital Ibadan, a geriatric psychiatric clinic runs once a week and patients have
full diagnostic work up including appropriate laboratory tests and neuropsychological tests.
Treatment consists of pharmacological and non-pharmacological modalities. Caregivers
are counseled on how to handle legal issues, driving and administration of properties of
patients who can no longer administer them. Psychoeducation is carried out on how to handle
behavior disturbances. Information is also given on the course and prognosis of the illness.
We apply rational use of anti-dementia and antipsychotic drugs. Our treatment approach is
multidisciplinary consisting of physicians, nurses and social workers. A general observation
is that follow-up appointments are not kept for long, probably because we do not meet the
caregivers’ expectation of permanent cure or because of deterioration that sets in later. Even
though there are currently few nursing homes, most patients are still cared for by family and in
one unpublished survey it was observed that caregivers who have to leave or cut down on work
to take care of their relatives are often burdened. Most families also have to pay out-of-pocket as
health insurance coverage is poor and in some cases unavailable.

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**BPSD in Japan**


**BPSD in Latin America**


**BPSD in Argentina**


**BPSD in Mexico**


**BPSD in Brazil**


**BPSD in Africa**


# MODULE 8: Long-term care (LTC)

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Key messages

- Behavioral and psychological symptoms of dementia (BPSD) are very common in Long-Term Care (LTC) facilities. They include aggression, agitation, depression, anxiety, delusions and hallucinations, pacing, screaming, wandering and apathy. Some of these cause great distress for the person, their family, caregivers and the staff.

- Comprehensive biopsychosocial assessment of BPSD is a necessary first step to ascertain causative factors and consider optimal interventions. Indeed, without preliminary assessment data, one cannot evaluate the effectiveness of an intervention.

- It is important to try to rule out worsening of a chronic medical or psychiatric disorder, a new medical condition, delirium, pain, constipation, substance abuse or withdrawal, hearing and vision problems and adverse effects of medications.

- Careful selection of appropriate assessment tools can help to craft and carry out empirically-based, person-centered care plans to help alleviate BPSD. Screening and assessment measures may require varying levels of training to administer and score correctly. Necessary training as well as appropriate follow-up is essential.

- The needs of persons with dementia and BPSD are often extensive, with complex etiologies and triggers. A range of pharmacological and non-pharmacological approaches are required.

- There is a substantial body of evidence in support of the use of psychosocial interventions for BPSD. These approaches are indicated as first-line management for all emotional and behavioral disturbances in individuals with dementia.

- Psychotropic drugs (antipsychotic drugs in particular) are often prescribed too often and for too long. Evidence has shown that psychotropic drugs can be safely discontinued in many cases.

- Education on drug efficacy and safety, increased psychosocial interventions and medication review are effective strategies to optimize psychotropic drug prescription in long-term care.

- Follow-up assessment is vital to determine whether interventions have been sufficient, whether further complications have arisen, or to determine whether the need for continued treatment (particularly with pharmacological interventions) is warranted.

- Interdisciplinary treatment teams have been shown to provide superior care in community and hospital-based aged care settings; research evidence is accumulating about their efficacy in long-term care settings. Interdisciplinary teams differ in structure and process to multidisciplinary treatment teams.

- A wide variety of disciplines may participate in an interdisciplinary care team. While the exact professional mix within teams may vary due to many factors (e.g. patient mix, funding constraints), key elements of interdisciplinary knowledge, communication, and respect remain.

- There is increasing evidence that geriatric mental health training and education can improve staff understanding of disease and treatment needs, improve job satisfaction and self-worth, reduce the potential for challenging behaviors and improve quality of life of older people living in long-term care.
Introduction

Behavioral and psychological symptoms of dementia (BPSD) are highly prevalent in long-term care (LTC) settings. Approximately 60% of older adults in LTC facilities have dementia and the prevalence of BPSD among individuals with dementia in LTC is as high as 90% in some studies, with a median prevalence of any behavior symptom of 78% (Seitz et al., 2010). Such symptoms cause significant loss of quality of life and present formidable challenges to the staff of LTC facilities charged with their care (Ballard et al., 2001). A detailed description of BPSD and their prevalence can be found in Module 2 (Clinical Issues). It is important to note that behavioral and mood symptoms can range from mild to very severe and that interventions for individuals and service planning must take this into account. The seven-tiered model of management for BPSD (Brodaty et al., 2003) is very helpful with regard to service planning.

Principles of good care

Long-term care facilities in different regions and countries include a variable mix of social, physical, clinical and mental health services (Brodsky et al., 2002; Brodsky et al., 2003; Wikler and Hirschfeld, 2002). The economic challenges of providing health care contribute to disparities within and across countries. And yet, despite differences in culture, resources and government policy among nations, a review of international consensus documents on human dignity, elder well-being and human rights as well as specific mental health practice guidelines, conducted under the auspices of the International Psychogeriatric Association Task Force on Mental Health Services in Long-Term Care Homes, revealed broad support for certain core principles (Gibson et al., 2010). These include that: (1) residential care should be situated within a continuum of services which are accessible on the basis of need; (2) there should be an explicit focus on quality of care in long-term care facilities; and (3) quality of life for the residents of these facilities should be a primary objective. The following observations taken from this search for principles of good care are of particular interest to the issue of BPSD in facility-based long term care:

- Much of the work on improving residential care has focused on aspects of basic physical care, such as decreasing pressure sores, countering weight loss, removing physical and chemical restraints, etc.
- Complex needs that must be addressed in a high quality care system include interactions among increased physical frailty, multiple chronic illnesses, cognitive decline and emotional distress.
- High quality mental health care in nursing homes is possible only where overall care is of high quality (American Geriatrics Society and American Association for Geriatric Psychiatry, 2003).
- The person-centered care movement, which originated in the context of caring for older people with dementia in the United Kingdom, is now influential in many parts of the world, including Australia, parts of Western Europe and North America (Dewing, 2004).
- Quality of care implies the ability to compromise and to balance the needs of all parties involved, including the recipient of care, family members and care providers (Sandberg et al., 2002).
• The stigma of LTC residency persists, to the detriment of those individuals who need this level of support in order to survive. Issues of stigma and discrimination are compounded for those individuals who are aging with a mental disorder (Graham et al., 2003).

**Environmental design**

In 2001, Marshall published an important statement on the design of environments for people with dementia. She recommended that facilities should be designed in such a way as to compensate for disability, maximize independence, reinforce personal identity, enhance self-esteem and confidence, demonstrate care for staff and welcome relatives and the local community (Marshall, 2001). Fleming and Purandare (2010) recently reviewed 57 studies and synthesized the evidence with respect to environmental design in LTC. They concluded that the empirical evidence supports the recommendations that long-term facilities for people with dementia should be designed and constructed with the following features in mind:

• Where it is necessary to provide for the safety and security of the residents by confining them within a secure perimeter, this should be achieved by means of unobtrusive security measures that maximize the feeling of control over the environment.

• Those parts of the facility which are accessible to the residents should contain a variety of spaces that provide the residents with differing ambience, size and function.

• Each resident should have the opportunity to have a single room and be allowed to personalize that room.

• Residents should be able to see the features that are most important to them from the location(s) where they spend most of their time.

• The levels of stimulation should be adjusted to minimize unhelpful stimulation and optimize helpful stimuli with the periodic availability of high levels of illumination.

• It is desirable that the facility should be small, have a homelike appearance, provide opportunities for engagement with the ordinary activities of daily living, and have an outside space that is accessible to the resident when accompanied by a member of staff.

**Screening and behavioral assessment**

A wide range of assessment tools may play a role in the successful management of BPSD within LTC settings. Psychological testing can be used to screen for the presence of BPSD. It can also ascertain the extent to which the frequency and severity of such symptoms distress the person with dementia or their caregivers. More formal assessment tools can assist in gathering information on a broader range of cognitive impairment or emotional distress that can help identify etiologies and suggest possible interventions. Targeted measures (e.g., for assessment of delirium) may form a critical component of the management of BPSD. In order to put into place effective strategies to manage BPSD, it is necessary to accurately measure the nature of the behaviors, their frequency and timing, and potential triggers and underlying causes. Just as important is the accurate documentation of the circumstances in which such behaviors do not occur. Measurement of the medical, psychological, social and environmental context of the unique individual with dementia is critical.
BPSD occur against a background of the resident’s premorbid personality and their premorbid social and occupational functioning. Quite often, current behaviors can be understood in the light of these pre-existing personal characteristics. In addition, the type of dementia that they have is likely to have certain characteristic effects on their mental state and behavior. For instance, people with dementia of the Alzheimer’s type (DAT) tend to exhibit stereotypic personality changes, including increased neuroticism (Robins, Wahlin and Byrne, 2010). Assessment of BPSD also needs to take into account the often transient nature of many symptoms (Aalten et al., 2005). Symptoms may vary across time of day and across staff members, and may change in response to the person’s health status and environment. The utility of screening and assessment measures to augment clinical charting of BPSD is critical. Such measures can provide a standardized, objective record of what are often changeable behaviors and circumstances over time. This can allow for the most effective, empirically-based interventions to be enacted. The use of measures demonstrating sensitivity to change is important here.

LTC settings may be staffed and supported by a wide range of health care professionals, who may have varying degrees of familiarity with assessment instruments. Measurement issues such as standardized administration of measures, and the distinction between screening and diagnostic assessment may be unfamiliar to many staff members in such settings (Pachana et al., 2010). For example, screening often involves the use of cut scores, and more involved psychological assessment batteries make use of normative data to place an individual’s scores within the context of relevant peer groups. In contrast, individual-centered (idiographic) approaches to assessment do not make use of such normative data. In addition, sensory and communication difficulties of residents may make meaningful assessment challenging.

Useful steps to take in assessment

Ideally, the treatment team should take some time to discuss why assessment of an individual is required. Is it to measure frequency and timing of the behavior? What are the levels of distress in the resident? Are there related consequences of behaviors (such as falls or care refusals)? Determining what questions need to be answered can help ascertain which tools will work best for the purpose.

Is assessment actually necessary? Has the reported problem reached the threshold for assessment and management? Trivial or transient problems might not need assessment. Sometimes an assessment is requested by a certain party when not all parties agree that it is needed.

Who “owns” the problem? Does the resident have the problem, does the staff have the problem or does the family have the problem? It is important to identify who has the problem, otherwise the assessment and management may be off target. Which problem should be assessed? The resident might have a number of interrelated problems. It is often impractical to assess them all. It is best to identify the one worst problem and focus on it. If there has been an acute change it is important to rule out a new medical condition or exacerbation of a chronic medical or psychiatric disorder.

Next, a discussion of who will administer the assessment, and to whom, should follow. Some assessments may require a referral (for example, to a psychologist) if staff deem this necessary. But a wide range of measures designed for use in nursing home contexts may be used by nursing staff. Having multiple assessors, if implemented well, can help mitigate against any biases of a single assessor.
Use of informants is often vital in gathering information about past behavior and preferences, as well as current insights into possible triggers for behaviors. However, caution is warranted as no one person can have wholly accurate knowledge of the person with dementia’s internal state. For example, in a study by Chopra and colleagues (2008), the self-report of persons with mild cognitive impairment (MCI) or DAT, as reflected in a Mini-Mental State Examination (MMSE) mean score of 24 was compared with the reports of family members or close associates. Results in this study indicated significant disagreement on all items of the Geriatric Depression Scale (GDS-15), with the exception of the item pertaining to memory problems. Thus proxy reports, which are often essential when assessing persons with significant cognitive impairment, should be used with due care.

It is important also to distinguish between screening measures, which usually only give information about the possible presence of a symptom, and more fully developed assessment measures, which can provide diagnostic indications and more robust symptom and behavior levels and severity assessment. Screens are often designed to be administered by a wide range of health professionals, and are relatively straightforward to deliver, score and interpret. More complex assessment tools may provide vital information necessary to implement management strategies, but require administration, scoring and interpretation by specific professionals, including the use of normative data to gauge whether an individual’s presentation is outside that expected. When measures are inappropriately treated as screens, harm may be done. For example, while MMSE scores may be interpreted using simple cut-off scores, such scores obtained without reference to age and education specific normative data (Crum et al., 1993) are highly misleading, as are interpretations stemming from them.

Finally, once interventions have been put into place, it is essential to ascertain their efficacy and determine when they are no longer needed. This is particularly true of pharmacological measures implemented to assist in behavior management. The woeful statistics on the number and duration of antipsychotic use in older adults in nursing home care speaks to the need to implement steps to gather data on when medication may no longer be required (Porsteinsson, Ryan, Ismail, and Tariot, 2003). This statistic also speaks to the need for greater use of non-pharmacological interventions for BPSD in LTC.

Resources to access and evaluate assessment tools

There are a variety of resources available on screening tools. These include reference texts, compilations of screening tests and individual reviews and analyses in the published literature (e.g., Burns et al., 2004; Neville and Byrne, 2001; Pachana et al., 2010; Snowden et al., 2003). Review articles on particular issues such as behavioral pain assessment tools (e.g., Zwakhalen et al., 2006) may be particularly useful.

If measures are required to be translated from the original language of publication, great care must be taken to ensure linguistic equivalence and adequate psychometric properties are established (Stewart, 2008). Metaphorical language may be difficult to get across in another cultural context, and factors such as varying levels of schooling or familiarity with testing in general may limit utility in new contexts. The World Health Organization has useful guidelines for appropriate practices to follow when translating a measure (World Health Organization, 2007).
Unfortunately, adequate research on the use and efficacy of screening tools and assessment measures in LTC lags behind clinical demands. More work on determining the clinical efficacy of screening instruments is required, particularly with respect to clinical outcomes, for example in terms of symptom reduction or delay in disease progression (Pachana et al., 2010). The development of more internationally applicable instruments specifically to assist with management of BPSD is particularly needed.

In day-to-day practice within nursing homes, care staff require adequate resources to be able to provide high-quality care to residents. This includes the provision by the facility of necessary assessment tools, the regular review and updating of said measures, and any attendant training that is necessary to use such tools appropriately. Policies on the assessment of residents within facilities should be developed with the input of staff and should be reviewed periodically.

- Using assessment tools appropriately in nursing facilities requires input from all levels of care providers as well as relatives of residents, with respect to decisions around use of such tools as well as collaborative cooperation in their administration and interpretation.
- Ultimately, the quality of data obtained with respect to BPSD is only as good as the tools used to measure their parameters. Particular care should be taken in the choice of test and its implementation for individuals for whom sensory impairments, communication issues or other unique contextual issues could bias the data obtained.
- Key decision points in the care of an individual with BPSD are when to test, how to assess, and what follow-up actions are required given the assessment data obtained. An important use of assessment is to determine not only the starting points and nature of interventions, but also when they are no longer required, or when they need to be altered to reflect changing circumstances.

**Non-pharmacological interventions**

This section of the module supplements Module 5, Non-pharmacological treatments, by providing a brief overview of non-pharmacological treatments for BPSD that are supported by evidence from randomized controlled clinical trials conducted in LTC settings. The categories of non-pharmacological interventions that are included in this overview are: training programs for LTC staff; individualized assessment and care planning; psychosocial activities; exercise; music therapy; and other forms of sensory stimulation.

**Training programs for long-term care staff**

Several studies have examined the effects of providing training to LTC staff on strategies to decrease BPSD in residents. The strategies that form the content of training vary in their specificity and comprehensiveness, and in some cases represent overarching care approaches. For example, the recent Caring for Aged Dementia Care Resident Study (CADRES) conducted in 15 LTC facilities in Australia evaluated the effects of two care approaches, dementia care mapping and patient-centered care, when compared to usual care for LTC residents with dementia. Eight months following the intervention both dementia care mapping and patient-centered care groups had significantly lower scores on agitation when compared to the usual care group who deteriorated during the study period (Chenoweth et al., 2009). The interventions did not show a significant difference on BPSD symptoms measured on the Neuropsychiatric Inventory (NPI).
Another study examining the effects of nurse training and coaching also demonstrated some benefit in some symptoms of agitation (McCallion et al., 1999).

**Individualized assessment and care plans**

Comprehensive evaluation of BPSD with individualized treatment planning has been evaluated in LTC residents. There is evidence that agitated behaviors can be reduced when care includes assessment of agitated behaviors and potential causes, followed by implementation of psychosocial activities that address the perceived causes and take into consideration the patient’s background and interests (Cohen-Mansfield et al., 2007). Symptom management has also been demonstrated when care includes a review of BPSD symptoms and possible causes, along with adherence to guidelines for medication management and an activity program (Rovner et al., 1996).

**Psychosocial activities**

Psychosocial activity programming has been evaluated in a number of studies in LTC as a potential intervention for managing BPSD. Psychosocial activity programming includes regular participation in personally meaningful or enjoyable events, either on one’s own or as a member of a group. Improvement in symptoms of BPSD was demonstrated in a small study that provided a one-to-one pleasant event activity that had been tailored to an individual’s interests for 30 minutes, three times weekly (Lichtenberg et al., 2005). Another study found that participation in group-based validation therapy reduced agitation following three months of treatment when compared to usual care (Toseland et al., 1997).

**Exercise programs**

There is evidence to support the physical health benefits of exercise programs for older adults with dementia in LTC. In addition, several studies have evaluated the effects of exercise on BPSD symptoms, including agitation, aggression and negative affect. A program involving daytime exercise along with changes to nighttime nursing routines was compared to a nighttime intervention alone. A significant reduction in agitated behavior was observed in the group who received the daytime exercise intervention (Alessi et al., 1999). Physically aggressive behavior was reduced among residents who participated in exercise and physical activity rather than receiving usual care in another small study (Landi et al., 2004). A study that looked at residents’ negative affect found that mood was improved by participation in an individualized exercise program, as compared to participation in a walking program or social conversation (Williams et al., 2007).

**Music therapy**

Two studies have demonstrated a beneficial effect for music on BPSD in LTC residents. Participation in a group music therapy intervention accompanied by movement was beneficial in reducing symptoms of agitation for the participating individuals as compared to those who received usual care (Sung et al., 2006). A second study of music therapy also found significant reductions in BPSD symptoms when music therapy participants were compared to residents whose caregivers received support sessions (Raglio et al., 2008).
Sensory stimulation

Sensory stimulation involving visual, tactile or olfactory senses has also been examined in LTC. Agitation was reduced with the use of aromatherapy using lemon balm when compared to administration of placebo oil (Ballard et al., 2002). Therapeutic touch consisting of gentle massage without aromatherapy has also been found to have some benefit for reducing agitation or aggressive behaviors (Woods et al., 2005; Hawranik et al., 2008).

Conclusions

There is a small body of evidence to support the use of several non-pharmacological interventions for reducing selected BPSD in LTC (notably agitation, aggression and negative affect). These interventions include training LTC staff in BPSD management, individualized assessment and treatment planning, exercise and a variety of pleasant psychosocial activities and sensory stimulation. Some of the more concrete or tangible interventions (exercise, psychosocial interventions and sensory stimulation) have been found to have an effect on BPSD while they are being administered, rather than over a longer term. There is certainly a need for interventions that can be used to reduce agitation and aggression and elevate mood in the moment, both as crisis management interventions and as a means of enhancing quality of life. More programmatic interventions (staff training, individualized assessment and care planning) may be expected to have a more generalized effect, changing the prevalence and intensity of BPSD within the LTC facility as a whole on an ongoing basis. There is need for greater understanding of the potential of approaches such as dementia care mapping and patient-centered care to change the culture of behavioral response in LTC overall. This is particularly critical as a focus for future research, since the availability of resources and staffing to support more piecemeal interventions may be more or less feasible in various LTC settings, and more or less efficacious in the long term.

Pharmacological interventions

This section of the module supplements Module 6, Pharmacological Treatments, by providing a brief overview of pharmacological treatments for BPSD that are supported by evidence from randomized controlled clinical trials conducted in LTC settings. Among all LTC residents, up to 40% of individuals receive antidepressants, 30% receive antipsychotics and 30% receive benzodiazepines (Conn et al., 1999; Pitkala et al., 2004; Seitz et al., 2009). Therefore, an understanding of the efficacy and indications for use of these medications in the LTC setting is of great importance, especially considering the increased risk for adverse events such as stroke, falls and death (Gill et al., 2007; Gill et al., 2005; Herrmann et al., 2004; Rochon et al., 2008; Schneider et al., 2005). The categories of pharmacological interventions that are included in this overview are: atypical antipsychotics, antidepressants, anticonvulsants, cholinesterase inhibitors and other medications. A review of pertinent negative studies in the literature will also be presented.

Atypical antipsychotics

The atypical antipsychotics are the most extensively studied pharmacological intervention for BPSD. There is good evidence from large scale randomized controlled trials conducted in LTC demonstrating efficacy for risperidone (Brodaty et al., 2003; Holmes et al., 2007; Katz et al.,
1999), olanzapine (De Deyn et al., 2004; Street et al., 2000) and aripiprazole (Mintzer et al., 2007) in the reduction of agitation and aggression in patients with AD. Daily doses of risperidone 1–2mg and olanzapine 5–10mg, and aripiprazole 5–10 mg are significantly better than placebo at reducing BPSD (De Deyn et al., 2004; Street et al., 2000; Mintzer et al., 2007). Aripiprazole 10mg daily has been shown to be significantly better than placebo in treating psychosis, though less is known of its effects on agitation and aggression (De Deyn et al., 2005). The antipsychotic quetiapine has been studied in two randomized controlled trials both of which did not demonstrate any significant benefit over placebo (Tariot et al., 2006; Zhong et al., 2007).

**Antidepressants**

While a number of studies have shown the use of antidepressants to manage depression in AD (Lyketsos et al., 2003; Magai et al., 2000) and some limited evidence for antidepressants in treating BPSD in community-based or hospitalized geriatric psychiatry populations (Seitz et al., 2011), there is limited evidence supporting the use of antidepressants for the management of BPSD in LTC. Currently, only one randomized controlled clinical trial investigating the use of the antidepressant, sertraline, for treatment of aggression and agitation specifically in LTC exists with efficacy similar for sertraline when compared to haloperidol (Gaber et al., 2001). More studies are needed to determine the efficacy of antidepressants for treating agitation and aggression.

**Anticonvulsants**

The use of anticonvulsants for the treatment of BPSD in LTC has included randomized controlled trials of carbamazepine (Tariot et al., 1998), valproic acid (Porsteinsson et al., 2001; Tariot et al., 2005) and oxcarbazepine (Sommer et al., 2009). Of these, only carbamazepine 300mg daily has been shown to be significantly better than placebo in reducing BPSD in AD (Tariot et al., 1998).

**Cognitive enhancers**

The cholinesterase inhibitors (ChEls: donepezil, galantamine, and rivastigmine) and the N-methyl-D-aspartate (NMDA) receptor antagonist, memantine, have been examined as potential treatments for BPSD. Results suggest that the ChEIs have a slight effect in decreasing BPSD and caregiver burden in patients with mild to moderate AD living in the community (Cummings et al., 2006; Cummings et al., 2004; Herrmann et al., 2005; Mega et al., 1999; Trinh et al., 2003). However, there is no evidence to support a role for the use of ChEls to treat BPSD in the LTC setting, perhaps because this is predominantly the moderate to severe spectrum of AD (Tariot et al., 2001). In a 24-week study of moderate to severe AD patients living in LTC, there was no significant change in BPSD in individuals taking donepezil vs. placebo as measured by the Neuropsychiatric Inventory (Tariot et al., 2001).

**Other medications**

There have been several randomized controlled clinical trials examining the use of non-conventional psychiatric medications for the treatment of BPSD in AD. Sex hormones have been targeted as potential moderators of agitation and aggression. One study has shown 100 mg daily of cyproterone, an antiandrogen, to be significantly more effective than haloperidol
in reducing general aggression in institutionalized AD patients, though the authors note that further studies are required to determine efficacy in patients with more severe BPSD (Huertas et al., 2007). Additionally, estrogen therapy (0.65–2.5mg daily) was shown to be significantly greater than placebo in improving aggressive behavior in a short-term study (Kyomen et al., 1999). This finding was not reproduced in a later study utilizing transdermal estrogen patches (50mcg–100mcg daily) (Hall et al., 2005), suggesting more research is required to determine the effectiveness of estrogen therapy in management of BPSD. Propranolol, a beta-adrenergic antagonist has been found to be significantly greater than placebo in reducing agitation/aggression and anxiety in patients with probable AD in LTC at doses of 30–120mg daily (Peskind et al., 2005). The authors note, however, that initiation of this treatment must be closely monitored for contraindications of beta-adrenergic antagonist therapy in a very frail population (Peskind et al., 2005). The antihypertensive, prazosin, was shown to be significantly greater than placebo in reducing BPSD in the LTC setting at doses of 1–6mg daily (Wang et al., 2009). This finding was based on a relatively small sample size at one facility, prompting further investigation of the positive result. Melatonin, a naturally occurring hormone with a known role in regulating circadian rhythm, has been studied as a possible treatment for BPSD in AD with poor results, showing no significant difference compared to placebo in studies conducted in LTC (Gehrman et al., 2009; Serfaty et al., 2002; Singer et al., 2003).

Conclusions

There are a number of studies of various pharmacological treatments for BPSD in LTC. Medications that have been shown to be significantly more effective than placebo in managing BPSD in the LTC setting are the antipsychotics risperidone, olanzapine, and aripiprazole and the anticonvulsant carbamazepine. Cyproterone, estrogen, prazosin and propranolol have also demonstrated promising results in single studies but require further investigation. It must be noted that use of these pharmacological interventions must be closely monitored in LTC due to the risk of severe adverse events such as increased risk of falls, stroke and death (Gill et al., 2007; Gill et al., 2005; Herrmann et al., 2004; Huybrechts et al., 2011; Rochon et al., 2008; Schneider et al., 2005), particularly with antipsychotics. Non-pharmacological interventions (Module 6) such as staff training, psychosocial therapy, music therapy and exercise should be employed whenever possible given availability of resources and severity of patient symptoms. It may be necessary to implement pharmacological treatments in specific cases, such as physical aggression, as the non-pharmacological interventions may have limited efficacy in this setting and may be difficult to utilize in acute situations where patient safety may be at risk.

Optimizing the use of psychotropic medications

In LTC homes, 65%–78% of the patients with dementia use at least one psychotropic drug (Pitkala et al., 2004; Kim and Whall, 2006; Lovheim et al., 2006; Selbaek et al., 2007; Zuidema et al., 2007). A majority of 83% of psychotropic drug use was chronic (Van Dijk et al., 2000). Recent data confirmed that 85% of antipsychotic drug users continue to use them for a 6-month period, and 12% for a period of two years (Wetzels et al., 2011). Psychotropic drug prescription is correlated with the degree of neuropsychiatric symptoms (Kim et al., 2006; Kamble et al., 2009; Nijk et al., 2009), environmental correlates, such as bed capacity of the
nursing home and physicians’ drug prescription policy (Wood-Mitchell et al., 2008). Physicians are more likely to prescribe psychotropic drugs in patients with Neuropsychiatric Symptoms (NPS) in a situation where the staff is additionally distressed, and when staff apply pressure to the physician to prescribe drugs (Cornege-Blokland et al., 2010). Physicians themselves often consider the possible benefits of antipsychotics to outweigh the risk of side effects (Cornege-Blokland et al., 2010).

High rates of sustained psychotropic drug use, especially antipsychotics, suggest non-adherence to international guidelines. In general, antipsychotic drugs and benzodiazepines are prescribed too often and for too long. Although some psychotropic drugs might be overused, there may also be underuse in some cases. Notably antidepressants, that are recommended in cases of depression in dementia, have the risk of being underused, because depression is not always detected (Smalbrugge et al., 2006).

The high rates of psychotropic drug use, in relation to the limited efficacy and considerable side effects, warrant a growing awareness of medical doctors, professionals and bodies representing professionals to be cautious with psychotropic drug prescription (Banerjee, 2009). People with dementia should receive psychotropic medication only when they really need it (Salzman et al., 2008). Optimization of psychotropic drug prescription is vitally important. In cases where drugs are prescribed too often and too long, optimization means reduction of over prescription. In other situations optimization means detailed assessment of indication, dosage, duration and side effects of psychotropic drugs, assisted with techniques like medication review to assess the appropriateness of prescription.

**Strategies for optimization/discontinuation**

In general, when symptoms have subsided, some psychotropic drugs can be safely discontinued after a while. Supportive evidence exists that discontinuation of psychotropic drugs, i.e., antipsychotics (Ballard et al., 2004; Bridges-Parlet et al., 1997; van Reekum et al., 2002; Ruths et al., 2004; Thapa et al., 1994) and anxiolytics is possible for most individuals without increase of NPS. In a recent randomized controlled withdrawal study (Dart-AD study—Ballard et al., 2009), in 165 long-term care patients, no differences were found between the antipsychotic-continuation group compared to the withdrawal group, but mortality rates were lower in the latter group. In a subgroup of patients with high-level of neuropsychiatric symptoms (NPI score > 14), withdrawal was accompanied by an increase/relapse of neuropsychiatric symptoms, suggesting that antipsychotics should only be prescribed in severe cases.

Three strategies had been found to facilitate discontinuation of psychotropic drugs: education on efficacy and safety, medication review and enhanced psychosocial care (sometimes carried out in combination).

**Education**

In five out of seven randomized controlled trials, education on effects and adverse events of psychotropic drugs by pharmacists to physicians and nurses is effective in reduction of psychotropics in general (Avorn et al., 1992), antipsychotics (Fossey et al., 2006), hypnotics (Eide et al., 2001) and more, specifically in reduction of the percentage of inappropriate psychotropic drug prescription (Crotty et al., 2004). However, in two other studies education
did not have any effect on psychotropic (Hagen et al., 2005), antipsychotic (Ray et al., 1993; Hagen et al., 2005) or benzodiazepine (Hagen et al., 2005) drug prescription.

Medication review
Medication review can be used to decrease psychotropic drug prescription or to optimize psychotropic drug therapy. Medication review, using the expertise of a pharmacist, has been shown to increase physicians’ and nurses’ knowledge and awareness of medication (Verrue et al., 2009). In Australia, drug review—multidisciplinary case conferences by pharmacists, geriatriecs, general practitioners (GP) and residential care staff on the quality of prescribing—has been shown to optimize drug prescription in patients with dementia or pain related medication problems in long-term care facilities (Westbury et al., 2010). In an Irish randomized controlled clinical trial in 22 nursing homes, particularly aimed at reduction of inappropriate prescription, a pharmacist drug review resulted in a significant, considerable and cost-effective decrease in inappropriate psychotropic drug use (Patterson et al., 2010).

In four out of the five randomized controlled trials aimed at reduction of the volume of psychotropic drug prescription, medication review appeared to be effective in the reduction of the number of antipsychotic drugs (Ray et al., 1993; Westbury et al., 2010; Roberts et al., 2001; Schmidt et al., 1998), hypnotic drugs (Schmidt et al., 1998), benzodiazepines (Westbury et al., 2010; Roberts et al., 2001), and antidepressants (Schmidt et al., 1998). It is interesting to note that in the largest study, of 1,600 nursing home residents with the most detailed interventions (Westbury et al., 2010), the effects are rather small, with only significant reduction of antipsychotics of 5% and no significant effect on benzodiazepine and antidepressant use. In only one large randomized controlled clinical trial in which medication review is carried out solely by the pharmacist (without any interaction with other care workers), did the prescription rates not change (Furniss et al., 2000).

Enhanced psychosocial care
In four out of four randomized controlled trials, enhanced psychosocial care was effective in reduction of psychotropic (Rovner et al., 1996; Kovach et al., 2006) or antipsychotic drugs (Fossey et al., 2006; Bird et al., 2007), with rather large reductions of 14–24%. The enhanced psychosocial care encompassed implementation of a dementia care program (Rovner et al., 1996), stepwise treatment of unmet needs (Kovach et al., 2006), a variety of patient-centered individualized psychosocial interventions, such as behavioral management techniques, person-centered care, reminiscence, involvement of family carers (Fossey et al., 2006). Studies in which these three strategies were combined (Fossey et al., 2006; Ray et al., 1993; Westbury et al., 2010; Roberts et al., 2001) seemed to do just as well in terms of a reduction of psychotropic drugs, but the number of studies is too small for comparison of effect sizes.

Recommendations
General considerations of psychotropic drug prescription and discontinuation:
- As proposed by several international guidelines, psychosocial interventions should be the first-line treatment, and psychotropic drugs should only be prescribed in very severe cases of aggression/psychosis in dementia or in delirium, and/or when an acute intervention (with behavior that causes immediate risk to patients or staff) is needed.
• Optimization of psychotropic drugs includes limited use, i.e. only in neuropsychiatric symptoms in which prescription is necessary, such as with severe symptoms where other non-pharmacological interventions has been tried and turned out to be unsuccessful.

• It is essential to obtain informed consent. In most cases this involves a substitute decision-maker. Requirements vary in different jurisdictions with written consent becoming a more frequent requirement or recommendation for some psychotropic medications.

• Choose the type of psychotropic drug with a valid indication and dosage.

• Monitor symptoms ideally utilizing assessment instruments and be vigilant for adverse events.

• Prescribe psychotropic drugs for a limited amount of time, in accordance with guidelines.

Drug review:

• Psychotropic drugs should be reviewed regularly. Ideally medication review should be carried out by a physician, pharmacist and nurse although this will depend on staff availability.

• Medication review should preferably include the full evaluation of medication appropriateness of each psychotropic drug, i.e., indication, effectiveness, dosage, directions, drug-drug interactions, drug-disease interactions, duplication, duration and expense.

Education regarding efficacy and safety:

• Education should be provided to staff by pharmacists, and other psychogeriatric experts such as old-age psychiatrists, elderly care physicians, and experienced general practitioners.

• Education should include knowledge transfer on the modest efficacy and considerable side effects of psychotropic drugs, and ways to assess efficacy and adverse events/side effects in an individual patient.

• In the broader context, professionals (general practitioners and other physicians working in long-term care facilities) should receive education to equip them for their role in the management of the complexity, co-morbidity and severity of mental and physical disorders in those residing in care homes. This should be available as part of continuing professional development (Banerjee et al., 2009).

Organization of long-term care (Banerjee et al., 2009):

• Local specialists (elderly care physicians, old age psychiatrists, geriatricians) should be available for outreach services that support primary care staff. This extension of service needs the capacity to work routinely in all facilities where there may be people with dementia. They may be aided by pharmacist input into homes to support or carry out regular drug reviews, including psychotropic drugs.

• Work to overcome financial and organizational barriers to implement non-pharmacological interventions in long-term care.

• Maximize use of qualified staff in long-term care facilities.
Role of the interdisciplinary team

A wide variety of health professionals have roles to play in providing optimum care to address BPSD within LTC settings. Ideally, these individuals function within a cohesive team to assess potential causes of behaviors and symptoms of concern and to provide continuously updated care plans, including potential interventions to lessen such behaviors and symptoms. No single individual or profession can bring the necessary wide diversity of knowledge and strategies to the unique issues raised particularly by BPSD. The needs of persons with dementia can be complex, evolve over time, and require novel approaches to care. Interdisciplinary teams are a key component in such care. LTC settings may be staffed by a wide range of health care professionals, often augmented by consulting health care professionals as well as community and volunteer workers. There is strong evidence from the broader field of geriatric medicine that there are unique advantages to care provided to older adults by cohesively functioning multidisciplinary or interdisciplinary teams. Such multidisciplinary models are particularly efficacious in treating older individuals with complex medical and/or psychiatric co-morbidities (e.g., Draper and Low, 2005; Grahn, Ekdahl and Borquist, 2000; Lidell and Fridlund, 1996; Rubenstein, Stuck, Sui and Weiland, 1991).

While most literature on multidisciplinary or interdisciplinary team functioning and efficacy is within the broader realm of geriatric medicine, a few studies highlight their benefits within LTC (e.g. Schmidt et al, 1998, 2002). Benefits include reduced use of antipsychotics and benzodiazepine hypnotics, more appropriate antidepressant medications and lower prevalence of BPSD. Effective interdisciplinary collaboration in a multidisciplinary team can be undermined by a variety of influences. These may include a lack of understanding of one another’s roles, infringement at professional boundaries, limited communication and poorly coordinated work within the team (Zwarenstein, Goldman and Reeves, 2009). All members of the team need to be informed about the medical, emotional and social needs of the patients within the contexts of their families, communities and cultures. In turn the members of the team need to have knowledge of and respect for various discipline-based approaches, so as to maximize benefits to patients in their care.

It is also important to emphasize that strong and clear leadership is essential for effective interdisciplinary collaboration and teamwork (Reeves et al., 2010). The leadership role can be challenging including the need to deal with conflict at multiple levels. Reeves et al., (2010) outline the historical development of the professions, noting that each has separate professional responsibilities and different lines of management reporting. They describe the need for changing leadership within teams depending on the patient’s needs. For example, medical leadership is appropriate when medical needs are paramount, but when the focus is on social care other team members may need to take the lead. Many qualities are necessary for successful leadership including the capacity to utilize a variety of leadership styles. One important characteristic is the capacity to explore team motives and beliefs in accomplishing a change or perceived vision of success (Oliver, 2006). Leaders must be able to critically appraise team processes and outcomes on the path to achieving shared goals. In the increasingly complex world of healthcare adequate training in leadership skills for senior staff is essential.
Differences between multidisciplinary and interdisciplinary teams

The terms multidisciplinary and interdisciplinary are often used interchangeably, but this is not the case as each type of team is distinct. Furthermore, research has shown each type of team to have differential impacts on patient care and outcomes. It is important to note that some teams utilize a mixed model which incorporates elements of both of these approaches.

In a multidisciplinary team, varieties of disciplines work in the same setting and provide care to the same patients, but each discipline operates with considerable independence. For example, each discipline may pursue their own assessment of the patient and generate a discipline-specific treatment plan, implemented and reviewed with little input from other team members. Team members may share information with each other, but there is no attempt to generate a common treatment plan or coordinate implementation of the plan more systematically. Multidisciplinary teams are hierarchically organized, with a designated team leader (commonly a physician). This individual is responsible for overseeing the team and its functioning. According to Zeiss (2003), in such multidisciplinary team settings, team members feel responsible only for the clinical work of their own discipline, while not sharing a more cohesive sense of shared responsibility both for patient care as well as the functioning and effectiveness of the team itself.

An interdisciplinary team is characterized by a much higher degree of collaboration in the care of patients. Team members work together across their various disciplines to devise, implement and evaluate a care plan for their patients. Knowledge of each discipline's unique skill sets and strengths as well as areas of overlapping competence are more fully realized on an interdisciplinary team. This in turn leads to improved understanding of the possible ways each member might contribute to individual aspects of patient care. Within interdisciplinary teams, leadership functions are shared among members and Zeiss (2003) stresses that there is an expectation that everyone will be committed to both the clinical content of the program as well as the team’s method of working together. Such teams routinely will set aside time to review the process of team functioning, with a view to resolving issues between team members or with respect to conflicts in philosophy of care, before these erode the efficacy of the team and negatively impact care. Within such an interdisciplinary structure, all team members are assumed to be colleagues, and there is no hierarchical team organization. For a detailed review of interdisciplinary teams see Zeiss and Steffen (1998).

Disciplines and how they contribute to interdisciplinary treatment of BPSD

General Practitioners/Primary Care Physicians

General practice physicians provide primary care for acute and chronic illness across ages and genders, and although individual terms may vary, “general practitioner” and “primary care physician” are among the more common terms for such individuals. Within LTC settings such physicians are often the primary source of medical care. Within the Netherlands, medical care in nursing homes is provided by specially trained elderly care physicians, with specific competencies in psychogeriatrics, geriatric rehabilitation and palliative care (SOON 2010).

Geriatricians

Geriatricians specialize in treating individuals over age 65 and often act in a consulting role within LTC settings, although in some countries and contexts their role may be greater. In
In the United States a set of Minimum Geriatric Competencies in eight content domains (which include cognitive and behavioral disorders, medication management, hospital care for older adults and palliative care) have been endorsed by such bodies as the American Geriatrics Society, and the American Medical Association (Leipzig et al., 2009).

Old Age Psychiatrists (Geriatric psychiatrists, psychogeriatricians)
Geriatric psychiatry involves treatment of disorders of affect, behavior, cognition and perception in older adults. The psychiatrist’s medical training affords an appreciation of the mental health issues that may be associated with physical disorders as well as complications from surgical procedures, including delirium. Psychiatrists are also likely to look for drug interactions before suspecting a psychiatric etiology, and like geriatricians may be able to spot ways in which medication use can be more judicious (Jeste et al., 1999).

Nurses
Nursing practice incorporates the application of knowledge, skills and attitudes towards effecting improved care of persons with a wide range of illnesses within a broad range of settings, including LTC. Nurses often take responsibility for care management and on-going assessment, monitoring symptom presentation, responding to functional or medication issues, liaising with families and other professionals. There are a number of levels of recognized nursing practice spanning generalist and advanced as well as specialist areas of practice such as geriatric and mental health nursing.

Nursing assistants/Care workers
Nursing assistants/care workers generally work under the direction of a registered nurse and assist with patient care and activities of daily living. Historically they have had minimal training in aspects of both mental health and dementia, including BPSD.

Psychologists and Neuropsychologists
Clinical psychology is concerned with the assessment and treatment of mental illnesses, whereas neuropsychologists are particularly focused on cognitive and behavioral disturbance. Geropsychologists are specialists in aging mental health issues; in the United States, there is a specialist group of psychologists in long-term care (see links at the end of this module) and guidelines for psychological care are developing in many countries (e.g. Lichtenberg et al., 1998). With respect to BPSD, psychologists offer particular skills in conceptualizing prompts for such symptoms as well as devising care plans that include behavior management, communication, and environmental management as key strategies.

Social Workers/Welfare Officers
Social work competencies with older adults include case management (involving linking patients with services to meet their psychosocial needs), counseling and therapy, addressing family and social support concerns and advocacy. Issues such as financial abuse and working through of advanced care directives may be facilitated by social workers. Geriatric social workers are increasingly involved in program development within LTC settings (Leipzig, 2009).

Occupational Therapists
As a discipline, occupational therapy promotes health and addresses disability and illness through enabling people to perform meaningful activities or to work to resume former roles
and occupations. Within LTC settings, occupational therapists may focus on activities of daily living or self-care tasks such as feeding or dressing. Occupational therapists work with assistive devices to assist with such activities and can often offer expertise in modifying the LTC environment to facilitate independence.

Physical Therapists/Physiotherapists
Physical therapists or physiotherapists are concerned with physical illness or other conditions impairing movement and limiting the ability to perform activities of daily living. Optimizing physical functioning and maintaining safe mobility are key goals for physical therapists within LTC settings. Physical activity in LTC residents has the potential to impact positively on such concerns as falls risk (Nowalk et al., 2001) and pain management (Ferrell, 2004).

Music Therapists and Diversional Therapists
Music therapists are trained professionals who use all aspects of music, including its physical production, emotional sequelae and potential for social bonding, to help effect positive changes in mood and well-being.

Models of mental health care
Effective models of mental health service delivery to residents of long-term care facilities are needed to meet the growing number of individuals who will be cared for in such facilities in the coming decades. Bartels et al., (2002) report that multidisciplinary team models that emphasize the complementary contributions of different disciplines can greatly increase the efficacy of direct clinical consultation services to individual nursing home residents. The extant literature in general supports providing for the routine presence of qualified mental health clinicians in the nursing home. In addition, within such a multidisciplinary team context, the most effective mental health interventions are those that blend consultation with training and educational interventions for staff. Snowdon (2010) outlined six different models of mental health care provision:

- Consultative
- Consultation-liaison
- Nurse-centered
- Facility-based staffing
- Externally based multidisciplinary team
- Telepsychiatry services

Interprofessional collaboration approaches have been increasingly studied and have been the subject of several Cochrane reviews. Interprofessional collaboration approaches are characterized by interprofessional rounds, interprofessional meetings and externally facilitated audits of team functioning. Some method of reviewing functioning of the team itself, in addition to following clinical outcomes of the patient population served, is vital to effective team performance. IPC interventions can improve healthcare processes and outcomes, but further studies are needed to have a better understanding of the range of possible interventions afforded by such teams as well as their effectiveness, and in what circumstances these interventions may be most useful (Zwarenstein, Goldman and Reeves, 2009).
In the Netherlands, a well-structured and integrated model of an interdisciplinary treatment team operating within nursing homes has existed for some time. Comprised of specially trained elderly care physicians, nurses and psychologists, and with input from other disciplines, such teams have spearheaded both innovative care and empirical research on best practice models of care within nursing home settings, with BPSD as a strong focus (Hertogh, Deerenberg-Kessler and Ribbe, 1996).

Conclusions:

• An interdisciplinary team approach may improve treatment outcomes for a wide variety of presenting problems within LTC. Structured, empirically-based interventions for BPSD require interdisciplinary teams with particular interest and commitment to this type of care (Lawlor, 2002).

• Ultimately, the quality of such interventions is dependent on teams which have been able to work out a common set of objectives and approach to practice. Successful treatment relies on open communication and interplay between team process and competence in care provision.

• There is good evidence that interventions work best when tailored to people’s interests and skills. For those with advanced dementia, this information must be sought from a family member.

**Education and training**

The recognition and treatment of mental illness in older people living in long-term care is challenged by the scarcity of trained staff working in this environment and the limited access to specialist health professionals such as old age psychiatrists, geropsychiatric nurse practitioners and neuropsychologists. Staff working in LTC are regularly challenged by residents who have BPSD. Staff education and training offers the opportunity to equip staff to appropriately manage treatment and care of older people living with mental illness in long-term care.

There is strong evidence that LTC settings are predominately staffed by relatively unskilled workers supervised by registered nurses. These registered nurses may or may not have professional qualifications in geriatric mental health. The LTC workforce often has limited training and therefore poor understanding of disease, assessment and treatment of older people with mental illness (Hsu et al., 2005). Therefore there is a reliance on specialist services such as old age psychiatrists, neuropsychologists, behavioral management services and geropsychiatric nurse practitioners coming into the LTC setting to provide mental health services.

Several countries have tried to promote geriatric mental health education and training through the production of freely available education and training materials (see Canadian Coalition for Seniors’ Mental Health, 2006, and Australian Government Dementia Training and Study Centers, 2009). An important component of education and training programs is legislation that dictates curricula content and more importantly a legislative body that will approve the curricula (Hyser et al., 2010). An example of this is the National Council of Certified Dementia Practitioners that aims to promote national standards for comprehensive Alzheimer’s and dementia education (http://www.nccdp.org).
Evidence for best practice

Many of the successful training programs focus on dementia education. There are limited examples of successful programs focusing on broader geriatric mental illness. A number of key features of effective geriatric mental health education and training in LTC include:

- To be meaningful curriculum content must be directly planned with the audience for which it is intended.
- Education and training should be directed towards the assessed learning needs of the audience.
- Education and training is directed towards the needs of the residents living in LTC.
- The education and training materials should be related and incorporate the philosophy of care being promoted within the LTC setting.
- Organizational leadership and support is essential for maintaining learning and transfer of knowledge into practice.
- Training should be conducted as a whole of facility approach.
- Qualified people who have expertise in working with older people with mental illness, including dementia, should conduct training.
- Training sessions should be held at times that suit the intended audience.
- Content should be packaged to facilitate interactive classes with short and regular sessions that can be readily repeated.
- Positive staff behavior change can be encouraged through activities such as online learning and tip sheets indicating essential features.
- A dedicated education and training resource person may increase sustainability of programs (Beeber et al., 2010; Kuske et al., 2007; McAiney et al., 2007; Rampatige et al., 2009; Visser et al., 2008).

For more extensive reading refer to Moyle et al. (2010). In conclusion, staff working in LTC may benefit from an education and training program on geriatric mental illness. There is good evidence that education and training programs that utilize key success features help to encourage change in practice. Effective education and training relies on the commitment of LTC administration to such programs, offering opportunities for staff to attend and to integrate new knowledge into practice.

Guidelines

Overarching principles that promote and support the mental health of all LTC residents include facility-wide commitment to:

- Individualized, person-centered care
- Respect for family ties
- A biopsychosocial care planning framework
- A culture of caring that prioritizes quality of life
- A social and physical environment that is responsive to changing needs
- A focus on early intervention and prevention as well as treatment
• Staff training and development as necessary to enable the provision of informed and competent care (Canadian Coalition for Seniors’ Mental Health, 2006).

Guidelines focused on the care of individuals with mental disorders in LTC have been developed in a number of countries (e.g. Canadian Coalition for Seniors’ Mental Health, 2006; American Geriatrics Society/American Association for Geriatric Psychiatry, 2003; American Medical Directors Association, 2003). A series of useful evidence-based protocols have also been developed by the University of Iowa Gerontological Nursing Interventions Research Center (can be purchased via www.nursing.uiowa.edu/excellence/evidence-based-practice-guidelines). General guidelines for the care of individuals with dementia have also been developed in a number of countries including Australia, Canada and the United Kingdom.

Great efforts are made to produce these documents but ultimately the question is are they being implemented? National guidelines can be helpful but all implementation is really local in nature. The process of implementing best practices to improve quality of care is fraught with difficulty. Experts in knowledge translation are examining the processes required. Recently a Canadian group studied implementation in a LTC Home using a participatory action approach. Many of the outcomes were positive but some were unexpected, involving a change of culture on the units. These included the development of team huddles and the inclusion of personal support workers in team rounds (Sokoloff et al., 2012).

Caring for residents in LTC with BPSD and other mental disorders is often challenging. Concern about the quality of care around the globe led to the formation of an International Psychogeriatric Association (IPA) Task Force on Mental Health Services in Residential Care Homes (www.ipa-online.org). Discussions suggest that similar issues are relevant in almost all countries. These issues include inadequate staffing levels, lack of staff training regarding mental health issues, aging and poorly designed LTC homes, failure to identify and assess residents in a timely fashion, inappropriate use of psychotropic medications, and limited availability of mental health consultants. Although it may be difficult to implement all of the recommendations in this module or in guideline documents, given the challenges outlined above, each facility should strive to adopt as many as possible.
References and recommended reading

Introduction


Principles of good care


Environmental design

Screening and assessment


Non-pharmacological interventions


**Pharmacological interventions**


**Optimizing the use of psychotropic medications**


Role of the interdisciplinary team


**Education and staff training**


McCabe, M., Davidson, T., George, K. Effectiveness of staff training programs for behavioural problems among older people with dementia. *Aging and Mental Health*. 2007; **11**: 505–519.


**Guidelines**


Depression: clinical practice guidelines. American Medical Directors Association. 2003; Columbia, Maryland, United States.

National guidelines for the assessment and treatment of mental health issues in long-term care homes. 2006; Toronto, Ontario, Canada: Canadian Coalition for Seniors’ Mental Health.

The IPA Complete Guides to Behavioral and Psychological Symptoms of Dementia

Specialists Guide

MODULE 1: An introduction to BPSD
MODULE 2: Clinical issues
MODULE 3: Etiology
MODULE 4: Role of family caregivers
MODULE 5: Non-pharmacological treatments
MODULE 6: Pharmacological management
MODULE 7: Cross-cultural and transnational considerations
MODULE 8: Long-term care

Nurses Guide

The IPA Complete Guides to BPSD are available in three editions to meet a variety of practice needs.

Primary Care Physicians Guide

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