

The IPA Complete Guides to

# Behavioral and Psychological Symptoms of Dementia









# Nurses Guide







This publication is intended for the use of nurses and other professionals involved in the study and management of BPSD, and is not intended for use by patients and their caregivers. The International Psychogeriatric Association assumes no responsibility or liability in connection with the information and recommendations provided herein. Copyright 2007, 2012 International Psychogeriatric Association. All rights reserved under U.S. and International copyright laws. No part of this publication may be reproduced without the prior written permission of the International Psychogeriatric Association.

#### **Preface**

The number of older people in the world is rising quickly. In 2000, there were 600 million people aged 60 and over; there will be 1.2 billion by 2025 and two billion by 2050. In the developed world, the very old, those over age 80, is the fastest growing population group (World Health Organization, 2009). As these numbers increase over the coming years, there will be a dramatic rise in the number of people with dementia.

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 an area of great concern and presents tremendous burden to caregivers.

Cognitive symptoms of dementia have been widely studied. Recent years have seen the growth of research in functional changes in patients with dementia, including reduced ability to carry out normal activities of daily living. The recognition and appropriate management of the behavioral and psychological symptoms of dementia (BPSD) are important factors in improving our care of dementia patients. BPSD can result in suffering, premature institutionalization, increased costs of care, and significant loss of quality of life for patients and their families and caregivers.

BPSD are recognizable, understandable and treatable. The recognition and appropriate management of BPSD are important factors in improving our care of dementia patients and their caregivers and the rationale behind IPA's development of the BPSD series. *The Complete Guide to Behavioral and Psychological Symptoms of Dementia (BPSD)*, based on the *BPSD Educational Pack* that was originally distributed in 1998 and updated in 2002, was itself revised and updated in 2010 based upon literature reviews and new research by the contributors. The guides draw on material presented at the consensus conferences of the International Psychogeriatric Association (IPA), held in early 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.

In this guide, *The IPA Complete Guides to Behavioral and Psychological Symptoms of Dementia (BPSD)* – *Nurses Guide*, the extensive information found in the *Specialists Guide* (intended for all psychogeriatric professionals) was enhanced by describing complementary nursing care practices that are compassionate, culturally sensitive and evidence-based. These recommendations will aid nurses as they care for the patient, caregiver or lend support to nursing colleagues. This unique nursing perspective is critical to the overall care management of the patient and in strengthening relationships with patients and families.

We hope *The IPA Complete Guides to BPSD* and particularly the *Nurses Guide* will provide a useful overview of the presentation and causes of BPSD, offering constructive guidance on treatment interventions, both pharmacologic and non-pharmacologic, coupled with information on caregiver education and support. 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!

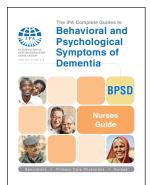
It is increasingly important that all professionals involved in the care and treatment of patients exhibiting signs of dementia have a thorough understanding of the *Behavioral and Psychological Symptoms of Dementia (BPSD)* and are provided with the best possible resources to guide them in developing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

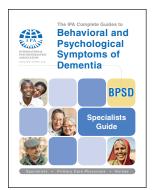
*The IPA Complete Guides to BPSD* is offered exclusively in electronic form. The advantages of a downloadable version include—

- 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 – 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

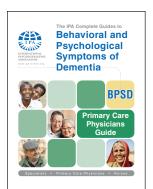


The IPA Complete Guides to BPSD – Specialists Guide is a comprehensive compilation of eight modules detailing the presentation and causes of BPSD, constructive guidance on pharmacological and non-pharmacological treatment interventions, and information on caregiver education and support. This is the 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

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 – 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 International Psychogeriatric Association's *The IPA Complete Guides to BPSD – Nurses Guide* is a specialized resource that supports the needs of the nursing, scientific and professional communities who care for the elderly with dementia. *The IPA Complete Guides to BPSD – Nurses Guide* has been made possible through the efforts of many nurse researchers and scientists. We gratefully acknowledge the work of the authors, contributors, reviewers, and editors.

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For additional information on these and other IPA resource materials, visit <a href="www.ipa-online.org">www.ipa-online.org</a> or contact IPA via email: info@ipaonline.org, by telephone: +1.847.501.3310 or fax: +1.847.501.3317.



#### **About IPA**

The mission of the International Psychogeriatric Association (IPA), founded in 1982, is to improve the mental health of older people everywhere through education, research, professional growth, advocacy, health promotion and service development.

IPA is a global, diverse professional healthcare community, communicating and collaborating 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 to discuss, share and research information about behavioral and biological aspects of geriatric mental health. IPA members work actively to promote advanced research, facilitate international consensus and understanding in psychogeriatric issues, and foster crosscultural understanding of the latest developments in the field.

As a member of IPA, professionals have access to a broad array of products, programs and services which may include the following: The *IPA Complete Guides to Behavioral and Psychological Symptoms of Dementia* series, IPA Members Area on the IPA website (online discussion and collaborative groups and other resources just for members) including the IPA Learning Portal (online educational programs and resources), *International Psychogeriatrics* (IPA's peer-reviewed journal), *IPA Bulletin* (newsletter) and the opportunity to participate in and attend IPA programs such as workshops, meetings and congresses worldwide at member reduced fees. For more information on IPA or to join, please visit www.ipa-online.org.

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This edition builds on *The IPA Complete Guides to Behavioral and Psychological Symptoms of Dementia (BPSD) – Specialists Guide*, but specifically addresses aspects that are of importance in nursing care provision. The aim of this guide is to provide guidance for nurses on how to structure nursing care for the benefit of the person with dementia and to strengthen nurses in their profession. Providing compassionate, culturally sensitive and evidence-based care to people with dementia is not easy. This guide will therefore also provide recommendations on how to support nurses in order to strengthen their relationship with patients and families. The guide will focus on three main areas:

- 1. Looking for possible reasons behind Behavioral and Psychological Symptoms of Dementia
- 2. Care approaches and nursing interventions in relation to BPSD
- 3. Support to formal and informal caregivers

Among nurses, the term Behavioral and Psychological Symptoms of Dementia (BPSD), has been widely discussed as well as questioned. The term is still, in many countries and among many clinicians and researchers, translated and used as "Behavioral Problems..." or "Behavioral Disturbances...", and sometimes as "...Psychiatric Symptoms...", even though the term BPSD says nothing about problems or malignancy (Finkel, 2000). BPSD however do create problems for the individual, family, staff and the community where the person with dementia lives. BPSD is a useful term as it is a concise umbrella name that embraces a wide range of cognitive symptoms and behaviors that people with dementia may display. It is a term used widely by health professionals and is therefore helpful in communication between professionals.

On the other hand, although BPSD is not a diagnostic entity there is a risk that BPSD is used as a diagnosis. This may result in an explanation for the behaviors and symptoms rather than a Need-Driven Dementia Compromised Behavior approach (Kolanowski, 1999) that conceptualizes the behaviors as potentially understandable and looks for the reason(s) that has lead to such behavior. For example, BPSD may have been a natural response to provocation such as undressing a person for a shower when s/he does not understand the situation. There is also a risk that we stop referring to behaviors and symptoms for what they actually are, such as someone being restless or having anxiety and instead calling everything BPSD. It is therefore imperative that we remember to carefully look behind the behavior and see the needs of the person in focus rather than rushing to treat the behavior. A list of behaviors and symptoms included in the term BPSD is shown in Table 1.

Table 1. Examples of behavioral and psychological symptoms

Behavioral	Psychological
Agitation	Anxiety
Calling out	Apathy
Crying	Delusions
Physical aggression	Depressed mood
Restlessness	Disinhibition
Screaming	Euphoria
Sexual inappropriate behavior	Hallucinations
Verbal aggression	Misidentifications
Wandering	Sleeplessness

From a clinical point of view, behavioral and psychological symptoms are often interrelated. For example, restlessness, wandering and agitation can be signs of anxiety. Also hallucinations and delusions can be viewed as psychotic symptoms while depressed mood and apathy can be considered depressive symptoms.

#### **Key messages**

- Behavioral and psychological symptoms of dementia (BPSD) are common and most people with dementia will experience some behavioral or psychological symptoms during the course of the disease.
- BPSD can often be prevented and successfully treated.
- BPSD cause significant distress to patients, their families and caregivers if not effectively managed.
- Management of BPSD requires understanding of the complex interplay of physical, psychological, interpersonal, social and environmental factors.
- Nursing care of people with dementia, and with BPSD, should be based on a person-centered care approach.
- Psychosocial interventions that are tailored to an individual's needs and abilities are the most effective and should be considered for all severities of BPSD.
- Nurses have an important role in supporting the family at home during early to moderate stages of dementia, and in residential care settings during its severe phases.
- To be able to provide high quality care, nurses have to be supported.

#### BPSD and the provision of nursing care

To assist in the provision of individualized care, it is important to understand the perspective of the person with dementia (*cf.* Kitwood, 1997; Keady, 1996), and by doing so, seek to understand the reason(s) behind dementia-related behaviors. People with dementia have, as a result of the

disease, difficulties communicating their wishes and needs. As a result it can be a significant challenge for nurses to interpret patient behavior and therefore their needs. When a person with dementia says or does something that we don't understand, we might see the behaviors as being without meaning. We might even explain the "meaningless" as being a part of the disease and the confusion. This may lead us to view people with dementia and their world as being without purpose and meaning (Asplund & Normann, 2011). The way we see people with dementia is, in turn, crucial for the way we meet and interact with them. Failure to understand, and inability to manage, such behaviors may lead to inappropriate use of psychotropic medication or use of limitations such as isolation, constraint and restraints.

Historically, the terms "behavioral problems" and "problematic," "disturbing," "disruptive" and "challenging behaviors" have been used in the health and research literature. Such terms reflect the problem that others have interpreting the meaning, rather than the individual's experience. The term BPSD reflects that the behaviors are connected to difficulties and symptoms related to dementia. There is no global intervention or quick-fix for managing different types of behaviors or symptoms, nor should there be. The main goal for nurses is instead to try to interpret and understand the behavior and adapt interventions individually to each person's needs.

#### Looking for possible reasons behind BPSD

#### Prevalence of BPSD

The prevalence of BPSD shows a great variability and tends to worsen with disease progression (Savva et al., 2009; Fernández et al., 2010). Although prevalence rates vary, BPSD are strong predictors of institutionalization and occur more frequently among nursing home residents. Studies in long-term care settings in Norway have shown that about 75% of the residents with dementia had a weekly occurrence of at least one type of BPSD (Testad et al., 2007). Previous studies have indicated up to 90% of residents display BPSD (for example Cohen-Mansfield et al., 1990; Eastley & Wilcock, 1997) and the reduction in BPSD may be explained by recent cultural change, characterized by an introduction of smaller specialized units with single rooms and private bathrooms, increased staff ratio and an emphasis on person-centered care.

The presence of BPSD, in turn, creates other difficulties. BPSD are correlated with an increased rate of falls, delayed onset of sleep and disruption of nighttime sleep. In addition, BPSD have been reported as a major stressor to nursing staff who care for persons with dementia. The picture of BPSD is very complex and there are no easy answers. Several factors are most certainly interrelated, such as the environment, the disease, and the nursing care provision.

#### BPSD as a result of reduced functional abilities

BPSD may result from a variety of underlying physical and cognitive causes. Besides the strong relationship to cognitive impairment, it is important to include the reduced functional ability that older people in general experience when interpreting underlying causes of BPSD. This includes reduced vision, hearing, mobility as well as incontinence and constipation. As people with dementia also have difficulties to express themselves and interpret communication, this might be another underlying cause. Their difficulties to express themselves also convey that they have difficulties expressing pain and other causes of discomfort.

#### Sensory impairment

Persons with dementia may have an age-related deterioration in sensory acuity (Van Hoof et al., 2010). It is thus important to compensate for sensory impairment as it may result in a misinterpretation of environmental stimuli leading to BPSD. More specifically, studies have shown that impaired vision is significantly related to visual hallucinations and verbally agitated behaviors (Chapman et al., 1999) and impaired hearing has been identified as a possible cause of agitation (Lyketsos et al., 2006). Visual or hearing problems that are managed by ensuring that spectacles and hearing aids are worn and adjusted correctly could thus decrease such behaviors (Cohen-Mansfield & Taylor, 2004). Further, it is essential that glasses with the correct prescription are kept clean, hearing aid batteries fresh, and the lighting adequate, to reduce the potential adverse effects of sensory impairment. There is also a risk that misinterpretations, delusions and hallucinations caused by sensory impairments contribute to the development of paranoia.

#### Difficulties in communication

People with dementia in particular also have difficulties interpreting and understanding verbal communication, as well as in expressing themselves. Although they have a decreased ability to communicate verbally due to perceptual, language and memory deficits, they retain an ability to communicate emotions non-verbally, even in the most severe stages of dementia (Magai et al., 1996). It is suggested that one-to-one interactions and mother tongue language are important in reducing agitated behavior (Runci et al., 1999). Furthermore, holding patients' hands, gently patting their arm, and talking to them in a calm and caring tone can also reduce agitation (Janet & Cheryl, 2005). Several studies have also found that non-verbal communication such as touch, eye contact and tone of voice is even more important than the spoken word when communicating with persons with dementia. Edberg et al., (1995) for instance found a harsh tone of voice was related to increasing verbal agitation, while a soft tone of voice was related to less verbal agitation. It seems important, then, to highlight not only what to do, but the manner in which it is done.

#### Pain

Another important underlying cause for BPSD is pain or discomfort that may elicit agitation. Pain can, however, be difficult to assess in persons with reduced ability to communicate. Studies conducted in acute care and nursing homes show that persons with dementia have fewer analgesics prescribed than persons who are cognitively intact. Recent research found that people with severe dementia did not experience less pain intensity compared to other stages of dementia; they demonstrated higher pain intensity than people without dementia and received less pain treatment (Husebo et al., 2008). People with severe dementia are at a high risk to suffer from severe pain and pain or physical discomfort could be minimized by regular analgesia, physical exercise, and change of position (Douzjian et al., 1998).

#### BPSD as a reaction to the environment

As persons with dementia have difficulty adapting to their environment, the environment has to be adapted to them. The literature is consistent when it comes to the environment as an etiological factor in BPSD, but is not consistent when describing adaptation of the environment as an intervention. Hall and Buckwalter (1987) clearly identify that inappropriate levels of

stimuli serve as stressors in three ways: over stimulation, under stimulation, and misleading stimuli. Therefore, environmental stimuli should be individually modified to compensate for the person's lowered stress threshold. Behaviors can be used as a barometer to determine the person's degree of tolerance. This can be seen in the light of Lawton and Simon's environmental press theory (1968). The less capacity an individual possesses, the more vulnerable s/he is to changes in the environment, conversely the more competent s/he is, the less vulnerable s/he is to changes in the environment. There needs to be a balance between environmental demands and the person's resources. That is, stimuli must be adjusted to the patient's changing abilities and needs.

#### BPSD as a reaction to the nurse-patient relationship

Nurses are one of the most important factors in the patients' environment, as patients must rely on nurses' care for their daily living. There are two important aspects to care, i.e., the task to be performed and the way the task is performed. Jecker and Self (1991) describe this in terms of caring for and caring about the patient. Findings from Hallberg et al., (1995) Armstrong-Esther et al., (1994) Coulson (1993) and others, suggest that nurse-patient interactions are focused mainly on the task to be performed, while the relational aspect, to acknowledge the person, is less present.

Several authors have emphasized the importance of seeing the person behind the diagnosis of dementia (Kitwood, 1997; Keady, 1996) and the way nurses view and treat the person with dementia has an impact on the relationship and interaction with them. The nurse can either enable or deny the "self" presented by the person (cf. Sabat & Harré, 1992). This in turn has implications for the way different behaviors are viewed. There is a risk that BPSD are interpreted only from the staff's perspective rather than as an expression of unmet need. For example, if a behavior is perceived as a consequence of the individual's illness there is a better chance that the behavior will be accepted. If, by contrast, the behavior is perceived to be willful or a conscious decision, there is a risk that the person with dementia will be viewed as unappreciative, resistive to help or manipulative (Nolan et al., 1996). The nurse's view of the patient and his or her behavior has a direct impact on the provision of nursing care which in turn can trigger or reduce different behaviors and symptoms.

# Care approaches and nursing interventions in relation to BPSD

Nurses use a variety of conceptual models or theories on which they base their understanding of behavioral and psychological symptoms associated with dementia. These models can guide research-based interventions and practice. Models identified in the literature include, among others, the Person-Centered Approach (PCA), the Validation Approach, the Need-Driven Dementia Compromised Behavior Model (NDB), and the Progressively Lowered Stress Threshold Model (PLST). Some of the models were derived from theory and others from practice. The empirical evidence varies. In this guide we will focus mainly on the Person-Centered Care Approach.

#### The person-centered care approach

The person-centered care approach was developed in the United Kingdom by Tom Kitwood and the Bradford Dementia Group. It teaches an understanding of the person and the behavior that the person is engaged in, rather than management of the behavior. The approach involves asking questions that pertain to the person's behavior like, "What does this tell us about the way in which the person is interpreting events or stimuli?" It requires nurses to look behind the behavior presented by the person to seek an understanding of what the behavior is communicating. Kitwood defines person centeredness as "...a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust" (Kitwood, 1997). The core components of personcentered care to people with dementia are, according to Edvardsson et al., (2008a), to:

- 1. Regard personhood in people with dementia as increasingly concealed rather than lost
- 2. Acknowledge the personhood of people with dementia in all aspects of care
- 3. Personalize care and surroundings
- 4. Offer shared decision making
- 5. Interpret behavior from the person's viewpoint
- 6. Prioritise the relationship to the same extent as the care tasks

Person-centered care thus requires that professional caregivers have full knowledge of each person's cultural and family values, personal life story, previous interests and skills, likes and dislikes (e.g., food, activities, personal care), and physical well-being (Brooker, 2004; Clarke, 2000; Day et al., 2000; Edvardsson et al., 2008a; Lawton, 2001; Moore, 1999; Morgan & Stewart, 1998). There is evidence supporting that agitation levels are lower if nursing home staff are trained in person-centered care (Wetle et al., 2005; Chenoweth et al., 2009), or personal care is designed to maintain each person's abilities and to compensate for lost ones (Wells et al., 2000). An example that supports person-centered care is: persons are bathed in the way they prefer, while minimizing their discomfort and speaking to them calmly (Sloane et al., 2004).

#### Dementia care mapping

Failure to provide care that supports well-being is designated by Kitwood as a "malignant social psychology" which undermines the ability to maintain personhood, in turn leading to emotional stress and increased behavioral "disturbances." In order to evaluate the care provided, an observational tool, Dementia Care Mapping (DCM), was designed in the UK and is used internationally. DCM methodology is well documented and seeks to evaluate care from the patient's perspective. The effectiveness of the method as well as the approach have been reviewed by Adams (1996) and Beavis et al., (2002), suggesting that the face validity and reliability of the method are good, but other aspects of validity can only be regarded as moderate. A recent study from Australia (Chenoweth et al., 2009) showed that staff training in either DCM or in person-centered care reduced agitation among residents, but DCM was not cost-effective. There is thus a need to also critically review the costs for the interventions that we perform and DCM has been criticized for being time-consuming and requiring considerable training and nursing resources.

#### Structured assessments and observations

As mentioned earlier, the primary focus for nursing care and planning interventions is the underlying causes of different behaviors. The recent literature is unambiguous in its conclusions: interventions must be individually tailored to the person and based on the individual's needs and abilities, and knowledge of the patient's present and past situation. Opie et al., (2002) further emphasize the importance of multidisciplinary teams and conclude that a combination of individually tailored medical, nursing and psychosocial interventions is preferred. Nursing interventions consequently must be seen as one highly important part of the patient's care. Thorough assessments and observations of the patient situation and needs are therefore essential. Two examples of assessment scales used to map BPSD are: Cohen-Mansfield Agitation Inventory (CMAI), (Cohen-Mansfield 1996) and the Neuropsychiatric Inventory (NPI), (Cummings, 1997). The CMAI consists of 29 items that are scored on a seven-point scale regarding how often it has occurred (1=never to 7=several times/hour) during the last two weeks. There is also a shorter 14-item version available for use in the nursing home environment: Cohen-Mansfield Agitation Inventory-Short Form (CMAI-SF).

#### **Cohen-Mansfield Agitation Inventory**

#### Items:

- · Paces, aimless wandering
- Inappropriate dress or disrobing
- Spitting (includes at meals)
- · Cursing or verbal aggression
- Constant unwarranted request for attention or help
- Repetitive sentences or questions
- Hitting (include self)
- Kicking
- Grabbing onto people
- Pushing
- Throwing things
- Strange noises (weird laughter or crying)
- Screaming
- Biting

- Scratching
- Trying to get to a different place
- Intentional falling
- Complaining
- Negativism
- Eating/ drinking inappropriate substances
- · Hurt self or others
- · Handling things inappropriately
- Hiding things
- Hoarding things
- Tearing things or destroying property
- · Performing repetitious mannerisms
- Making verbal sexual advances
- Making physical sexual advances
- General restlessness

The Neuropsychiatric Inventory consists of 12 items (there is also a 10-item scale available) that are rated concerning frequency (1-4 points) and severity (0-3 points), that are multiplied and can give a total score of 144 points. The higher score, the more severe symptoms. The scale can also be used to measure caregiver distress where the caregiver is asked how much stress the different symptoms cause (0=no stress to 5=severe stress) resulting in a maximum score of 60 points. Both scales require training before they can be used.



- 1. Delusions
- 2. Hallucinations
- 3. Agitation
- 4. Dysphoria
- 5. Anxiety
- **6.** Apathy
- 7. Irritability
- 8. Euphoria
- 9. Disinhibition
- 10. Aberrant motor behavior
- 11. Night-time behavior disturbances
- 12. Appetite and eating abnormalities

Also, a number of pain assessment tools and approaches for use with older persons who are cognitively intact as well as cognitively impaired have been published in evidence-based protocols and as medical guidelines. Nurses may now choose from a variety of assessment tools including verbal description scales, pain thermometer, and faces pain scales to better detect and manage pain in persons with dementia. These include, for example, the Assessment of Discomfort in Dementia Protocol, Abbey Pain Scale, Checklist of Nonverbal Pain Indicators and the Pain Assessment in Advanced Dementia Scale.

Several studies have explored the signs of pain/discomfort observed by nurses. Observations can include:

- **Facial expressions:** Slight frown, sad, frightened face, grimacing, wrinkled forehead, closed or tightened eyes, any distorted expressions, rapid blinking
- **Verbalizations**, **vocalizations**: Sighing, moaning, groaning, grunting, chanting, calling out, noisy breathing, asking for help
- **Body movements:** Rigid, tense body posture, guarding, fidgeting, increased pacing, rocking, restricted movement, gait or mobility changes
- **Changes in interpersonal interactions:** Aggressive, combative, resisting care, decreased social interactions, socially inappropriate, disruptive, withdrawn, verbally abusive
- Changes in activity patterns or routines: Refusing food, appetite change, increase in rest periods or sleep, changes in rest patterns, sudden cessation of common routines, increased wandering
- Mental status changes: Crying or tears, increased confusion, irritability, or distress
- Medication use: Especially psychoactive drugs that can interfere or interact with analgesics and elicit "unusual" pain behaviors as noted by family caregivers

While nurses have a central role in detecting pain or discomfort; nurses' personal characteristics, attitudes and knowledge can influence the likelihood of detecting pain.

#### Pharmacological approaches

Most BPSD can be managed with psychosocial interventions. However, pharmacologic treatments can be used, but only when other interventions have either failed or have inadequately controlled the BPSD, such as when the patients or caregivers are at risk for injury, or when there are distressing hallucinations or delusions, or when depression is present. It is thus important to be observant for signs of psychosis (delusions or hallucinations) or other conditions that need pharmacological treatment and contact a physician for consultation. Consideration should be given to how the BPSD may be affecting the patient's overall health status (Buhr & White, 2006), but the side effects and possible interactions are important when considering pharmacological treatment. For more information concerning pharmacological treatment, see Module 6 in the Complete Guide to Behavioral and Psychological Symptoms of Dementia (BPSD).

#### Strategies for communication

As mentioned earlier, patients with dementia have a decreased ability to communicate verbally due to perceptual, language and memory deficits. They also have difficulties understanding and interpreting others' communication. There are several aspects that can support their understanding and possibilities to interact with others. It is, however, of utmost importance to promote specific communication approaches for different ability profiles, and to adjust communication to the patient's ability.

#### General guidelines for communication

- Introduce yourself to the patient before conducting any procedure
- Always explain what you are going to do prior to moving into the patient's personal space to implement care
- Use a calm, reassuring tone of voice
- State sentences in a positive manner and avoid the use of commands including the word "don't"
- Provide opportunities for the patient to experience a sense of control
- Provide consistency in the daily routine and offering simple choices of foods and clothing whenever possible
- Provide reassurance as necessary; this is usually most effective from a family member or a health care provider with whom the patient is familiar and whose role is established
- If the patient can communicate verbally, determine which sense dominates the patient's perception of the world (visual, auditory, kinesthetic, olfactory, or gustatory) by listening to their descriptive words, then communicate with the patient through his or her preferred sense; this promotes a feeling of trust in the patient
- Use a non-threatening posture, position yourself at eye level with the patient and establish eye contact (unless culturally contraindicated)
- Do not "sneak up" on the patient or approach the patient from behind without announcing yourself
- The use of touch while providing care should be conducted in a respectful, careful, and unhurried manner. Feil (1992) found that gently stroking the patient from the ear lobe to the chin may stimulate the memory of a loved one, such as mother or spouse, and has a calming effect on the patient



The ideal environment for a person with dementia should be quiet, well lit, and a properly heated or cooled area (Dewing, 2009; Doody et al., 2001). A calm, supportive physical environment helps to prevent or minimize BPSD by ensuring that help is readily available. Furthermore, encourage independence while preserving safety, and promote meaningful activity and social engagement (Cohen-Mansfield & Werner, 1997; Whall et al., 1997). There is ample evidence that suggests that these goals are best achieved by providing special care units within long-term care facilities with features such as a homelike physical setting with small groups of patients, provision of exterior space, clearly marked access to conveniently situated bathroom, kitchen and toilet, access to safe walking paths and gardens, and maintenance of personal identity, background and culture through use of photographs (Ayalon et al., 2006; Beck et al., 2002; Dunn et al., 2002; Garland et al., 2007; O'Connor et al., 2009a and 2009b; Ragneskog et al., 1996; Sloane et al., 1995; Suhr et al., 1999; Teri et al., 2000).

There is no evidence that any single design feature has a distinct effect on BPSD. However, there is evidence suggesting that a homelike environment with a single bedroom is linked to a lower rate of anxiety and aggression (Zeisel et al., 2003). If personal facilities can offer privacy, a homelike setting, visual and tactile stimulation, and an outdoor facility, persons with dementia may have lower rates of agitation and other symptoms (Bicket et al., 2010). Soothing music in the environment is also found to be useful, as well as rocking chairs and recliners (Ballard et al., 2002; Joanna Briggs Institute, 2002a).

Simulated presence therapy and family videos can also reduce BPSD. For example, Camberg et al., (1999) reported that an audiotape that contains a relative's portion of a telephone conversation and leaves pauses that allows the person to respond to the relative's questions, has a significant effect on decreasing BPSD of persons with dementia. This approach has shown success in some individuals and not others, raising questions about individual characteristics, in particular, individual attachment styles (Peak & Cheston, 2002). It is important to consider the ethics of this approach, as there is deception involved. Discussion with family members prior to using simulated presence may help to reduce any potential concerns. Studies also showed that family-generated videotapes could significantly decrease BPSD during videotape exposure (Hall & Hare, 1997, Witucki & Twibell, 1997). It is however important to remember that such approaches can never replace the human contact.

#### **Activities of Daily Living (ADL)**

To enable the person with dementia to take an active part in their care, it is important to inform the person about what is about to happen; for example letting the person know in advance that it will soon be bath time. It is also important to choose the most suitable position of bathing for the individual, to obtain the person's consent, focus on his/her autonomy, try not to appear intrusive, and respect their privacy. The nurse's voice has to be gentle, explain what will happen next and negotiate care-giving, and keep talking during the ADL (Deudon et al., 2009). There is also evidence suggesting that identifying and eliciting retained ADL skills to reinforce and solidify skills, such as to support their previous habits, can be helpful (Chapman et al., 2004; Coyne & Hoskins, 1997; McGilton et al., 2003; Olazaran et al., 2004; Tadaka & Kanagawa, 2004).

As noted earlier, the implementation of daily care should focus on the "person, and not just the task." In addition, care should be adjusted to meet individual patient needs rather than forcing patients into a routine that is simply convenient for the formal or informal caregiver. Caregivers are encouraged to "listen" and "follow the lead" of the person with dementia. Care provided with this method will ultimately be more effective in meeting individual needs and be less stressful to the caregiver.

#### Hygiene

Hygiene activities such as bathing often create anxiety for the person with dementia and increase the risk of catastrophic reactions due to a high level of stress. The following guidelines can reduce the patient's level of stress and anxiety during hygiene activities and increase their safety:

- Ensure that the room is kept at an appropriate temperature. Keep the patient warm and covered as much as possible. Refill the tub with warm water as necessary throughout the bath period so it is consistently warm. If the patient is taking a shower, make sure that the water is set at the right temperature from the beginning. Encourage the patient to hold the shower grip by her/himself; a hand-held showerhead may provide a greater sense of control and consequently may be less frightening.
- Water temperature should be adjusted so that it is pleasant and the thermostat should be adjusted so that it is not possible for patients to scald themselves. Help the patient to feel the water before entering the tub or shower to assure that it is not too hot or cold.
- Make the bathroom area as homelike or "Spa-like" as possible.
- Explain the procedure one step at a time.
- Encourage participation throughout the procedure.
- If possible, try to maintain established habits. For example, a person who took tub baths throughout his/her life may find a shower confusing and frightening.
- Safety items should be installed to decrease the risk of falls: non-skid strips on the floor
  of the tub, grab bars for getting in and out of the tub or shower, a bath seat to allow
  individuals to sit above the water, or a shower chair if they prefer a greater sense of
  security.
- It is important to note that the presence of a person of the opposite sex can be distressing for the patient, for cultural, religious or emotional reasons.
- If the patient has arthritis or other medical conditions that impede entry into and out of the tub or shower stall, or cause pain, a mild analgesic 1/2 hour before the procedure may help.

#### Dining

Eating is essential to maintain adequate levels of nutrition, but is also an important factor for the sense of well-being and as a base for social interaction. The dining room environment is therefore very important. If it is too stressful, noisy, crowded or chaotic, there is a risk that the patient will be stressed and have difficulties focusing on the meal or may react with aggression. Goddaer and Abraham (1994) hypothesized that "relaxation" music would buffer the general noise level found in dining rooms in long-term care settings and that the music exerted a calming effect that could result in a reduction in the frequency of agitated behaviors.

In addition, Ragneskog and colleagues (1996) evaluated the effects of music during mealtime. They reported increased food intake, particularly significant for dessert, and a reduction in irritability, fear, panic and depressed mood. It is, however, important to note that the music should be low and calming as there otherwise is a risk that music could add to an already noisy environment.

Meals are complex situations, and besides the environment there are several other factors that could be stressful for the patient. The inability to identify a fork, knife, or the food itself (i.e., visual agnosia), can create anxiety, as can problems connected to dysphagia. A thorough mapping of the dining experience as a whole, taking both environmental as well as individual aspects into consideration, is essential. The behavior of the staff is another factor that can increase stress. It is important to try to focus on one patient at a time, and while helping one patient with the meal avoid being involved in conversations with others.

#### Finding the toilet

Incontinence and/or voiding in inappropriate places may result from the person's inability to find the toilet. To compensate, a list of simple measures can be implemented.

- Create opportunities for the person to find the way to the toilet, (e.g., clear pathways; leave the bathroom door open to make the toilet visible).
- Provide cues to find the toilet, (e.g., signs with pictures as well as words). If possible, camouflage doors that are for staff use in the same color as the wall and highlight toilet doors in a contrasting color. Ensure that if the person has limited mobility, she or he is seated close to the toilet.
- Use color contrast to help the person with dementia see the toilet seat. For example, the person may have difficulty seeing a white toilet against white walls and light colored floor. A brightly colored toilet seat will make it easier for the person to see and identify the toilet or use a contrasting color on the wall behind the seat.
- Cover or remove mirrors so that the patient isn't frightened or distracted from task by his/ her own reflection.
- Develop a toilet routine adjusted for the individual based on the person's history and habits.
- If night time incontinence is a problem, monitor and/or reduce fluid intake after 6 p.m.
- Monitor administration times of laxatives or other bowel stimulants to avoid accidents.
- When accidents occur, maintain dignity of the person and minimize "fuss" about the incident.

#### Rest and sleep

The balance between rest and activity is essential and it is important to arrange for short regular rest periods during mid-morning and mid-afternoon (Hall & Buckwalter, 1987). Some authors conclude that it is preferable for the person to take a nap or rest in a reclining chair since laying in bed may cause the person to become confused on waking, thinking it is morning and the beginning of a new day. For patients with sleeping problems, more daytime activity can improve sleep at night. Ensure that the room is at an appropriate temperature and that the noise level is reduced to a minimum. If possible, reduce the light during night-time to increase the impression that it actually is night.

#### Activity

For persons with dementia, as for others, activity has to be meaningful for the individual. The importance of everyday activities such as outdoor walks should not be neglected and a mixture of small group and individual activities that focus on individual interests should be implemented.

#### Interventions focused on senses

Psychosocial interventions can also involve complementary and alternative therapies (CAM). CAM interventions such as aromatherapy, massage, music and Snoezelen are considered to be useful as a means to increase relaxation, reduce agitated behaviors and as a stimulation activity (see Module 5 in the Complete Guide to Behavioral and Psychological Symptoms of Dementia (BPSD)). In recent years, there has been an increase in interest in using CAM. While CAM has been reported in a number of papers to have some benefits, there are also limitations reported in a large number of the research designs. Given the predicted increase in the number of people with dementia, there is a strong need to better understand how dementia and the associated symptoms, including BPSD, might be better managed using CAM. Our current knowledge of CAM interventions suggest that while they may have a place in reducing BPSD, they will not work all of the time for all BPSD symptoms or with all people with dementia. It is essential that such interventions are also used within a therapeutic environment; one where the importance of the nurse-patient relationship takes precedence and where assessment of the cause of the BPSD symptoms and evaluation of the intervention is given priority.

#### Aromatherapy

Aromatherapy is defined as the use of natural aromatic substances from the extraction of certain plants. Essential oils are the fundamental elements in performing aromatherapy and they are often regulated by a government agency. Aromatherapy has been introduced into the therapeutic environment as a sensory stimulation approach to modify behavior disturbance. Odors have been found to have an effect on behavioral and cognitive changes in people. For example, common smells affect the human autonomic nervous system (ANS); people can have immediate physiological changes to their blood pressure, muscle tension, pupil dilation, heart rate and skin temperature when the olfactory system is stimulated by odors (Heuberger et al., 2001). Heart rate is associated with the pleasantness factor; unpleasant odors can increase the human heart rate and skin conductance (Bensafi et al., 2002). Furthermore, odors significantly influence human mood (Heuberger et al., 2001). Unpleasant odor often results in negative mood state and pleasant odor induces positive mood (Robin et al., 1999). Pleasant odors can improve self-efficacy and working performance (Baron & Bronfen, 1994). However, aromatherapy sprayed or dispersed into the air may be of limited use in people with dementia as olfactory dysfunction is commonly associated with Alzheimer's disease and is an early sign in dementia with Lewy bodies (Gilbert et al., 2004).

The research literature demonstrates tensions with a number of studies reporting Lavender and Melissa essential oils having a sedative effect (Ballard et al., 2002; Bowles et al., 2002; Cavanagh & Wilkinson, 2005; Lin et al., 2007; Smallwood et al., 2001; Standen & Myers, 2004). Two studies have reported no change in agitation with the use of aromatherapy (Gray & Clair, 2002; Snow et al., 2004), while one study found some participants to have increased agitation and other participants to show a slight and insignificant decrease in agitation (Holmes et al.,

2002). Further research is necessary before a clear recommendation can be indicated for the use of aromatherapy in treatment of BPSD. However, any use must take into consideration the potential for the person with dementia to have impaired olfactory function and for an individualised approach rather than a one-fits-all approach. In addition, an assessment of the potential cause of the BPSD symptoms and evaluation of any aromatherapy treatment must have priority.

#### Massage

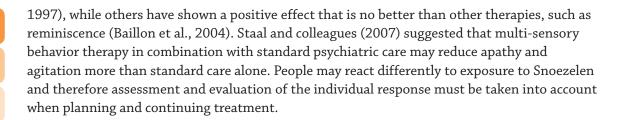
The earliest form of massage therapy is believed to have emanated from China and Egypt (Tuchtan et al., 2004). Massage reduces the physiological response to stress and decreases the output of adrenocorticotrophic hormone. It is assumed that massage may also provide comfort and reduce agitation in people with dementia. Evidence suggests that gentle hand massage with essential oils on the person's hands, back, and arms for three to 15 minutes a day with soft and calming verbalization could be useful. Massage method can be slow-stroke or rubbing, brushing, or kneading (Cohen-Mansfield, 2001; Kilstoff & Chenoweth, 1998; Kim & Buschmann, 1999; Rowe & Alfred, 1999; Scherder et al., 1998; Snyder et al., 1995a and 1995b). There are reports that upper body, including hand massage (Holliday-Welsh et al., 2009; Remington, 2002) and foot massage may reduce agitation in people with dementia (Moyle et al., 2011; Sutherland et al., 1999) and massage on the face and arms with lemon balm led to a reduction in agitated behaviors (Ballard et al., 2002). Such studies all report that massage is well-tolerated by people who display BPSD. However, before using any form of massage, the nurse therapist must take into consideration the person's response to being touched and having clothes removed for massage. Some cultures are non-touch cultures and therefore touch through massage may increase rather than decrease agitation.

#### Music as a psychosocial intervention

The therapeutic use of music has been advocated as an approach to inducing calm and therefore reducing BPSD in people with dementia. Such therapy has been defined as "the specialised use of music to change maladaptive physical, emotional and social behaviour to attain maximum levels of functioning" (Goodall & Etters, 2005, p.258). Studies have shown music has been effective in reducing agitation (Ledger & Baker, 2007; Raglio et al., 2008; Sung et al., 2006; Svansdottir & Snaedal, 2006), anxiety (Raglio et al., 2008; Svansdottir & Snaedal, 2006) and depression (Ashida, 2000). However, as the majority of this research is limited by research design and rigor, the results must be read with caution. Recent research using a randomised crossover design with music and reading control groups found the music program did not significantly affect agitation and anxiety in older people with dementia and there was no evidence that the music program was more effective than the group reading activity (Cooke et al., 2010). So while music may be useful as an adjunct to other psychosocial therapies, an assessment of the person's preferences for music and an evaluation of his/her response is essential.

#### Snoezelen

Snoezelen, or multisensory rooms, originated in the Netherlands in the 1960s in the area of learning disabilities. Although popular in some nursing homes as a means of reducing BPSD, the evidence for the use of Snoezelen is varied. Some studies have indicated Snoezelen can have a positive effect on the mood of people with dementia (Baker et al., 2001; Baker et al.,



#### Pets

Pet visits may also be beneficial. Two studies report a significant reduction of agitation with a dog present and significantly lower prevalence of verbal aggression and anxiety in pet-exposed patients (Churchill et al., 1999; Hart, 2006). However the pet must be certified and measures to taken to protect the patients and pets from harm. The research on pet therapy is limited and it is important to be aware that some patients do not like pets in general or specific animals, e.g. dogs.

#### White noise

White noise can also be used. Burgio et al., (1996) and Young et al., (1988) reported that relaxation and sleep were induced and nocturnal restlessness reduced with white noise, such as audiotapes (environmental sounds) or modified white noise (slow surf rate) at the bedside.

#### Physical restraints

Physical restraint are described in the literature to include the use of leather or cloth wrist and ankle restraints, full-sheet restraints, soft belts or vests, hand mitts, crotch/pelvic ties, suit harnesses, wheelchair safety bars, geri chairs and over chair tables (Poole and Mott, 2003). Use of restraints indirectly lessens older people's ability to participate fully in rehabilitation/re-enablement. It is also associated with reduced continence, pressure ulcers, immobility, more agitated behaviors, sometimes referred to as "paradoxical agitation," and infections that ultimately contribute to increased morbidity and mortality (Royal College of Nursing, 2008). The use of restraints might contribute to regressive, disorganized and unsocial behavior as well as loss of self-image, disorientation, withdrawal, feelings of discomfort, dependency, resistance, fear and anger (Bartels et al., 2003; Capezuti et al., 1996; Dawkins, 1998; Evans, 2010). Thus, physical restraint should be avoided.

The Joint Commission on Accreditation of Healthcare Organizations in the USA has stated that the following are the only acceptable reasons for restraint: 1) to avoid and/or prevent purposeful or accidental harm to the older person; 2) to do what is required to provide medically necessary treatment that could not be provided through any other means (Martin, 2002; Smith et al., 2003). To reduce the use of physical restraint in the management of BPSD, a personcentered care approach is recommended (see earlier discussion). Release from mandatory confinement indoors can help to decrease verbal and physical aggression, especially among men (McMinn & Hinton, 2000). Unlocking the exit door to outside walking paths can also help to decrease agitated behaviors (Namazi & Johnson, 1992).

Educational programs on restraint could result in changed staff knowledge and attitudes towards using restraints, and significantly decrease the use of restraints (Joanna Briggs Institute, 2002a and 2002b; Pellfolk et al., 2010).



# Caregiver support when caring for a family member living in the community and in residential/long-term care

Nurses have an important role in supporting the family, and in particular, the family caregiver. A need to improve outcomes for persons with dementia and their caregivers has resulted in a research field focused on developing and testing psychosocial interventions to assist both the person with dementia and his/her family caregivers (e.g., Bramble et al., 2011; Brodaty et al., 2003; Cooke et al., 2001; Mittelman, 2008; Pusey & Richards, 2001; Sörensen et al., 2002; Thompson et al., 2007). An understanding of the burden associated with caregiving has resulted in the more recent research being focused on assisting the family caregiver to maintain or improve well-being (Mittelman et al., 1996).

#### Family involvement in care

Moving to a nursing home does not necessarily mean an end to the stress experienced by family caregivers (Moyle et al., 2002). Following the placement, family members often have to learn to develop new roles and for some this can be particularly challenging. Nurses have a key role to play to support family caregivers to change their role from one of direct care tasks to a more supportive interpersonal role. Tensions can develop when family are not able to adapt to their new role. Several researchers (Bramble et al., 2009 and 2011; Gaugler & Ewen, 2005; Maas et al., 2004; Nolan et al., 2004; Robinson et al., 2007) have shown that family-staff partnerships in care can reduce staff-family conflicts, increase satisfaction and decrease staff and family stress. Maas and colleagues (2004) and Robinson and colleagues (2007) demonstrated that, through education and contractual partnership arrangements between staff and family, caregiving not only improved care for the person with dementia, but also resulted in more harmonious and productive partnerships, which benefit all.

The Family Involvement in Care (FIC) model developed by Maas and colleagues (2004) is driven by the theoretical frameworks of person-environment fit and role theory, and provides a framework for understanding the roles of family and staff when developing partnerships in care. The FIC model involves family and staff in a contractual partnership based on negotiation of therapeutic activities for the person with dementia. Such a model is supported by the work of Gaugler and Ewen (2005) that also demonstrates family caregivers who received emotional support were less likely to have negative experiences and thus, conflict with staff. The FIC model encourages the view that families themselves are clients and a potential resource for improving quality of care of the person with dementia, as well as reducing potential BPSD when the staff learns from family the preferences of the person with dementia. Key elements of the FIC program are the promotion and maintenance of the health of family caregivers through education and meaningful exchange with staff caregivers.

#### Support to nurses working in dementia care

A recent review of factors that attract and retain nurses in aged care and dementia care, by Chenoweth et al., (2010) concludes that a family-friendly learning environment that values and nurtures its nursing staff in the same way as nurses are expected to value and care for their patients and residents is critical in ensuring their retention in dementia and aged care. Thus, to be able to provide high-quality care, nurses, in turn, have to be supported.

There are studies showing an association between nurses' workload and the frequency of BPSD among residents (Edvardsson et al., 2008b). The study also showed an association between an "uncaring" care climate at the ward and the frequency of wandering behaviors. When nurses provide care that is mainly task-oriented and "uncaring" this may cause feelings of guilt and result in further withdrawal on the part of the patient. The tension between what the staff want to do and what they are able to do has also been described in the literature in terms of stress of conscience (Glasberg et al., 2007; Juthberg et al., 2010) and moral distress (Gustafsson et al., 2010; Lutzén et al., 2010), which in turn seems to be related to the development of burnout (Gustafsson et al., 2010). Dahlquist and co-workers (2009) found that stress of conscience includes a struggle to maintain self-respect and can lead to nursing staff unintentionally deceiving the patient. Thus, if staff are unable to provide the care they want to provide, their emotional and moral distress affects not only themselves, but also the patients in their care. Support to the staff would thus constitute a major step on the road to high-quality residential nursing care.

A key aspect of person-centeredness in dementia care is acknowledgement of the person's self as preserved, rather than lost, and striving to understand patient experiences and behaviors from their perspective (McCormack, 2004; Brooker, 2007; Edvardsson et al., 2008a). However, these are also the aspects that staff highlights as constituting their major difficulties (Edberg et al., 2008). Several studies from residential care and dementia care point to the usefulness of reflection as a tool for increasing understanding of the patients' experiences (Kalis et al., 2005; Bolmsjö et al., 2012), which could improve nursing practice and might also reduce stress (Gustafsson et al., 2009). Reflection is also described as one of the key components in clinical supervision (Kilminster & Jolly, 2000). Although clinical supervision is frequently highlighted in the literature (Fowler, 1996), empirical knowledge of dementia care is still limited. Considerable work has been conducted in the United Kingdom evaluating clinical supervision in other contexts, for example in mental health nursing (White et al., 1998; Buttleworth et al., 1996; Buttleworth et al., 1999). In recent years, clinical supervision has been introduced in several countries, thus acknowledging the nurses' need for support. In Australia, the Health Ministers' Advisory Council recommended that mental health services staff should have access to formal and informal clinical supervision (Winstanley & White, 2002). Even if clinical supervision is given in different ways in different settings, it can be an effective means of supporting nurses in their provision of care. It is important that nurses have the opportunity to reflect on patients as unique persons with lived experiences. Clinical supervision can facilitate this perspective in order to promote high quality in nurses' interactions with the patients.

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#### References

Adams, T. Kitwood's approach to dementia and dementia care: A critical but appreciative review. *Journal of Advanced Nursing.* 1996; **23**: 948–953.

Armstrong-Esther, C.A., Browne, K.D., McAfee, J.G. Elderly patients: Still clean and sitting quietly. *Journal of Advanced Nursing*. 1994; **19**: 264–271.

Ashida, S. The effect of reminiscence music therapy sessions on changes in depressive symptoms in elderly persons with dementia. *Journal of Music Therapy*. 2000; **37**: 170–182.

Asplund, K., Normann, H.K. Lucidity in people with severe dementia (In Swedish). In Edberg, A-K (ed): *Caring for people with dementia*. 2011; Studentlitteratur, Lund.

Ayalon, L., Gum, A.M., Feliciano, L., Arean, P.A. Effectiveness of nonpharmacological interventions for the management of neuropsychiatric symptoms in patients with dementia. *Archives of Internal Medicine*. 2006; **166**: 2182–2188.

Baillon, S., Van Diepen, E., Prettyman, R., Redman, J., Rooke, N., Campbell, R. A comparison of the effects of Snoezelen therapy on the agitated behaviour of patients with dementia. *International Journal of Geriatric Psychiatry*. 2004; **19**: 1047–1052.

Baker, R., Bell, S., Baker, E., et al. A randomised controlled trial of the effects of multi-sensory stimulation (MSS) for people with dementia. *British Journal of Occupational Therapy*. 2001; **40**: 81–96.

Baker, R., Dowling, Z., Wareing, L. Snoezelen: Its long-term and short-term effects on older people with dementia. *British Journal of Occupational Therapy*. 1997; **60**: 213–218.

Ballard, C.G., O'Brien, J.T., Reichelt, K., Perry, E.K. Aromatherapy as a safe and effective treatment for the management of agitation in severe dementia: the results of a double-blind, placebo-controlled trial with Melissa. *Journal of Clinical Psychiatry*. 2002; **63(7)**: 553–558.

Baron, R. A., Bronfen, M. I. A whiff of reality: empirical evidence concerning the effects of pleasant fragrances on work-related behavior. *Journal of Applied Social Psychology.* 1994; **24(13)**: 1179–1203.

Bartels, S.J., Horn, S.D., Smout, R.J., Dums, A.R., Flaherty, E., Jones, J.K., Voss, A.C. Agitation and depression in frail nursing home elderly patients with dementia: treatment characteristics and service use. *The American Journal of Geriatric Psychiatry*. 2003; **11(2)**: 231–238.

Beavis, D., Simpson, S., Graham, I. A literature review of dementia care mapping: Methodological considerations and efficacy. *Journal of Psychiatric and Mental Health Nursing*. 2002; **9**: 725–736.

Beck, C.K., Vogelpohl, T.S., Rasin, J.H., Uriri, J.T., O'Sullivan, P., Walls, R., Baldwin, B. Effects of Behavioral Interventions on Disruptive Behavior and Affect in Demented Nursing Home Persons. *Nursing Research*. 2002; **51**: 219–228.

Bensafi, M., Rouby, C., Farget, V., Vigouroux, M., Holley, A. Asymmetry of pleasant vs. unpleasant odor processing during affective judgment in humans. *Neuroscience Letters*. 2002; **328(3)**: 309–313.

Bicket, M.C., Samus, Q.M., McNabney, M., Onyike, C.U., Mayer, L.S., Brandt, J., Rosenblatt, A. The physical environment influences neuropsychiatric symptoms and other outcomes in assisted living persons. *International Journal of Geriatric Psychiatry*. 2010; **25(10)**: 1044–54.

Bolmsjö, I., Edberg, A-K., Lilja Andersson, P. The use of drama to support reflection and understanding of the residents' situation in dementia care: A pilot study. *International Journal of Older People Nursing.* 2012; doi:10.1111/j.1748-3743.2012.00333.x, *in press*.

Bowles, E. J., Griffiths, D. M., Quirk, L., Brownrigg, A., Croot, K. Effects of essential oils and touch on resistance to nursing care procedures and other dementia-related behaviours in a residential care facility. *The International Journal of Aromatherapy*. 2002; **12(1)**: 22–29.

Bramble, M., Moyle, W., McAllister, M. Seeking connection: family care experiences following long-term dementia care placement. *Journal of Clinical Nursing*. 2009; **18**: 3118–3125.

Bramble, M., Moyle, W., Shum, D. A quasi-experimental design trial exploring the effect of a partnership intervention on family and staff well-being in long-term dementia care. *Aging and Mental Health*. 2011; **15(8)**: 995–1007.

Brodaty, H., Green, A., Koschera, A. Meta-analysis of psychosocial interventions for caregivers of people with dementia. *Journal of the American Geriatrics Society*. 2003; **51(5)**: 657–64.

Brooker, D. What is person-centred care in dementia? *Reviews in Clinical Gerontology*. 2004; **13**: 215–222.

Brooker, D. *Person-centred dementia care—making services better.* 2007; London: Jessica Kingsley Publishers.

Buhr, G.T., White, H.K. Difficult behaviors in long-term care patients with dementia. *Journal of American Medical Directors Association*. 2006; **7**: 180–192

Burgio, L., Scilley, K., Hardin, J.M., Hsu, C., Yancey, J. Environmental "white noise": an intervention for verbally agitated nursing home persons. *The Journals of Gerontology: Series B.* 1996; **51B**:364–373.

Butterworth, T., Bishop, V., Carsson, J. First steps towards evaluating clinical supervision in nursing and health visiting. I. Theory, policy and practice development. A review. *Journal of Clinical Nursing*. 1996; **5(2)**: 127–132.

Butterworth, T., Carson, J., Jeacock, J., White, E., Clements, A. Stress, coping, burnout and job satisfaction in British nurses: Findings from the clinical supervision evaluation project. *Stress Medicine*. 1999; **15**: 27–33.

Camberg, L., Woods, P., Ooi, W.L., Hurley, A., Volicer, L., Ashley, J., McIntyre, K. Evaluation of Simulated Presence: A Personalized Approach to Enhance Well-Being in Persons with Alzheimer's Disease. *Journal of the American Geriatrics Society*. 1999; **47(4)**: 446–452.

Capezuti, E., Evans, L., Strumpf, N., Maislin, G. Physical restraint use and falls in nursing home persons. *Journal of the American Geriatrics Society*. 1996; **44(6)**: 627–633.

Cavanagh, H.M., Wilkinson, J.M. Lavender essential oil: A review. *Australian Infection Control*. 2005; **10(1)**: 35–37.

Chapman, F.M., Dickinson, J., McKeith, I., Ballard, C. Association among visual hallucinations, visual acuity, and specific eye pathologies in Alzheimer's disease: Treatment implications. *American Journal of Psychiatry.* 1999; **156**: 1983–5.

Chapman, S.B., Weiner, M.F., Rackley, A., Hynan, L.S., Zientz, J. Effects of cognitive communication stimulation for Alzheimer's disease patients treated with donepezil. *Journal of Speech, Language, and Hearing Research.* 2004; **47**: 1149–1164.

Chenoweth, L., King, M.J., Jeon, J.H., Brodaty, H., Steirn-Parbury, J., Norman, R., Haas, M., Luscombe, G. Caring for aged dementia care resident study (CADRES) of person-centred care, dementia care mapping, and usual care in dementia: a cluster-randomised trial. *Lancet Neurology*. 2009; **8**: 317–325.

Chenoweth, L., Yun-Hee Jeon, Y-H, Merlyn, T., Brodaty, H. A systematic review of what factors attract and retain nurses in aged and dementia care. *Journal of Clinical Nursing*. 2010; **19(1–2)**: 156–167.

Churchill, M., Safaoui, J., McCabe, B., Baun, M. Using a therapy dog to alleviate the agitation and desocialization of people with Alzheimer's disease. *Journal of Psychosocial Nursing and Mental Health Service*. 1999; **37**: 16–22.

Clarke, A. Using biography to enhance the nursing care of older people. *British Journal of Nursing*. 2000; **9**: 429–433.

Cohen-Mansfield, J. Conceptualization of agitation: results based on the Cohen-Mansfield Agitation Inventory and the Agitation Behaviour Mapping Instrument. *International Psychogeriatrics*. 1996; **8**: 309–15.

Cohen-Mansfield, J., Taylor, J.W. Hearing aids use in nursing homes, Part 2: barriers to effective utilization of hearing aids. *Journal of the American Medical Directors Association*. 2004; **5**: 289–296.

Cohen-Mansfield, J. Nonpharmacologic interventions for inappropriate behaviors in dementia: a review, summary, and critique. *American Journal of Geriatric Psychiatry*. 2001; **9**: 361–381.

Cohen-Mansfield, J., Werner, P., Marx, M.S. Screaming in nursing home residents. *Journal of the American Geriatrics Society*. 1990; **38(7)**: 785–792.

Cohen-Mansfield, J., Werner, P. Management of verbally disruptive behaviors in nursing home persons. *The Journals of Gerontology: Series A.* 1997; **52A**: M369–M377.

Cooke, D.D., McNally, L., Mulligan, K.T., Harrison, M.J.G., Newman, S.P. Psychosocial interventions for caregivers of people with dementia. Systematic review. *Aging & Mental Health*. 2001; **5**: 120–135.

Cooke, M., Moyle, W., Shum, D., Harrison, S., Murfield, J. A randomised control trial exploring the effect of music on agitated behaviours and anxiety in older people with dementia. *Aging and Mental Health*. 2010; **14(8)**: 905–916.

Coulson, I. The impact on the total environment in the care and management of dementia. *The American Journal of Alzheimer's Care and Related Disorders & Research*. 1993; **8**: 18–25.

Coyne, M.L., Hoskins, L. Improving eating behaviors in dementia using behavioral strategies. *Clinical Nursing Research*. 1997; **6**: 275–290.

Cummings, J.L. The Neuropsychiatric Inventory: Assessing psychopathology in dementia patients. *Neurology*. 1997; **48**:10S–16S.

Dahlqvist, V., Söderberg, A., Norberg, A. Facing inadequacy and being good enough: psychiatric care providers' narratives about experiencing and coping with troubled conscience. *Journal of Psychiatric and Mental Health Nursing.* 2009; **16(3)**: 242–247.

Dawkins, V. Restraints and the elderly with mental illness: ethical issues and moral reasoning. *Journal of Psychosocial Nursing and Mental Health Services*. 1998; **36(10)**: 22–27.

Day, K., Carreon, D., Stump, C. The therapeutic design of environments for people with dementia: a review of the empirical research. *Gerontologist*. 2000; **40**: 397–416.

Deudon, A., Maubourguet, N., Gervais, X., Leone, E., Brocker, P., Carcaillon, L., Robert, P.H. Non-pharmacological management of behavioural symptoms in nursing homes. *International Journal of Geriatric Psychiatry.* 2009; **24**: 1386–1395.

Dewing, J. Caring for people with dementia: noise and light. *Nursing Older People*. 2009; **21(5)**: 34–38.

Doody, R.S., Stevens, J.C., Beck, C., Dubinsky, R.M., Kaye, J.A., Gwyther, L., Cummings, J.L. Practice parameter: Management of dementia (an evidence-based review). Report of the Quality Standards Subcommittee of the American Academy of Neurology. *Neurology*. 2001; **56**: 1154–1166.

Douzjian, M., Wilson, C., Shultz, M., Berger, J., Tapnio, J., Blanton, V. A program to use pain control medication to reduce psychotropic drug use in persons with difficult behavior. *Annals of Long-Term Care*. 1998; **6**:174–179.

Dunn, J.C., Thiru-Chelvam, B., Beck, C.H.M. Bathing: pleasure or pain? *Journal of Gerontological Nursing*. 2002; **28(11)**: 6–13.

Eastley, R., Wilcock, G.K. Prevalence and correlates of aggressive behaviors occurring in patients with Alzheimer's disease. *International Journal of Geriatric Psychiatry*. 1997; **12(4)**: 484–487.

Edberg, A-K., Nordmark, Å., Hallberg, I.R. Initiating and terminating verbal interaction between nurses and severely demented patients regarded as vocally disruptive. *Journal of Psychiatric and Mental Health Nursing.* 1995; **2**: 159–167.

Edberg, A-K., Bird, M., Richards, D.A., Woods, R., Keeley, P., Davis-Quarrell, V. Strain in nursing care of people with dementia: nurses' experience in Australia, Sweden and United Kingdom. *Aging & Mental Health.* 2008; **12**: 236–243.

Edvardsson, D., Winblad, B., Sandman, P.O. Person-centred care of people with severe Alzheimer's disease: current status and ways forward. *The Lancet Neurology*. 2008a; **7**: 362–67.

Edvardsson, D., Sandman, P.O., Nay, R., Karlsson, S. Associations between the working characteristics of nursing staff and the prevalence of behavioral symptoms in people with dementia in residential care. *International Psychogeriatrics*. 2008b; **20**: 764–776.

Evans, D. Physical restraint and medical interventions. In Hughes R. (Ed), Rights, Risk and Restraint-Free Care of Older People. *Person-Centred Approaches in Health and Social Care*. 2010; London: Jessica Kingsley Publishers.

Feil, N. Validation Therapy. *Geriatric Nursing*. 1992; **13(3)**: 129–133.

Fernández, M., Gobartt, A.L., Balañá, M.; COOPERA Study Group. Behavioural symptoms in patients with Alzheimer's disease and their association with cognitive impairment. *BMC Neurology*. 2010; **28(10)**: 87.

Finkel, S. Introduction to behavioural and psychological symptoms of dementia (BPSD). *International Journal of Geriatric Psychiatry*. 2000; **15 (Suppl 1)**: S2–4.

Fowler, J. The organization of clinical supervision within the nursing profession: a review of the literature. *Journal of Advanced Nursing*. 1996; **23(3)**: 471–478.

Garland, K., Beer, E., Eppingstall, B., O'Connor, D.W. A comparison of two treatments of agitated behavior in nursing home persons with dementia: simulated presence and preferred music. *American Journal of Geriatric Psychiatry*. 2007; **15**: 514–521.

Gaugler, J., Ewen, H. Building Relationships in Residential Long-Term Care: Determinants of staff attitudes toward family members. *Journal of Gerontological Nursing*. 2005; **31(9)**: 19–33.

Gilbert, P. E., Barr, P. J., Murphy, C. Differences in olfactory and visual memory in patients with pathologically confirmed Alzheimer's disease and the Lewy body variant of Alzheimer's disease. *Journal of the International Neuropsychological Society.* 2004; **10**: 835–842.

Glasberg, A.L., Eriksson, S., Norberg, A. Burnout and 'stress of conscience' among healthcare personnel. *Journal of Advanced Nursing*. 2007; **57**: 392–403.

Goddaer, J., Abraham, I.L. Effects of relaxing music on agitation during meals among nursing home persons with severe cognitive impairment. *Archives of Psychiatric Nursing*. 1994; **8**:150–158.

Goodall, D., Etters, L. The therapeutic use of music on agitated behaviour in those with dementia. *Holistic Nursing Practice*. 2005; **19**: 258–262.

Gray, S.G., Clair, A.A. Influence of aromatherapy on medication administration to residential-care residents with dementia and behavioral challenge. *American Journal of Alzheimer's Disease and other Dementias*. 2002; **17(3)**: 169–174.

Gustafsson, C., Asp, M., Fagerberg, I. Reflection in night nursing. A phenomenographic study in municipal night duty registered nurses' conceptions of reflection. *Journal of Clinical Nursing*. 2009; **18**: 1460–1469.

Gustafsson, G., Eriksson, S., Strandberg, G., Norberg, A. Burnout and perceptions of conscience among health care personnel: a pilot study. *Nursing Ethics*. 2010; **17(1)**: 23–38.

Hall, G.R., Buckwalter, K.C. A conceptual model for planning and evaluating care of the client with Alzheimer's disease. *Archives of Psychiatric Nursing*. 1987; **1(6)**: 399–406.

Hall, L., Hare, J. Video respite for cognitively impaired persons in nursing homes. *American Journal of Alzheimer's Disease & Other Dementias*. 1997; **May/June**: 117–121.

Hart, L.A. Psychosocial benefits of animal companionship. *Handbook on Animal-Assisted Therapy* (Second Edition). 2006; Pages 59–78.

Hallberg, I.R., Holst, G., Nordmark, Å., Edberg, A-K. Cooperation during morning care between nurses and severely demented patients. *International Journal of Geriatric Psychiatry*. 1995; **4**: 78–104.

Heuberger, E., Hongratanaworakit, T., Böhm, C., Weber, R., Buchbauer, G. Effects of chiral fragrances on human autonomic nervous system parameters and self-evaluation. *Chemical Sense*. 2001; **26(3)**: 281–292.

Holliday-Welsh, D.M., Gessert, C.E., Renier, C.M. Massage in the management of agitation in nursing home residents with cognitive impairment. *Geriatric Nursing*. 2009; **30(2)**: 108–117.

Holmes, C., Hopkins, V., Hensford, C., MacLaughlin, V., Wilkinson, D., Rosenvinge, H. Lavender oil as a treatment for agitated behavior in severe dementia: a placebo controlled study. *International Journal of Geriatric Psychiatry*. 2002; **17**: 305–308.

Husebo, B.S., Strand, L.I., Moe-Nilssen, R., Borge, S., Husebo, S., Aarsland, D., Ljunggren, A.E. Who suffers most? Dementia and pain in nursing home patients: a cross-sectional study. *Journal of the American Medical Directors Association*. 2008; **9**: 427–33.

Janet, S., Cheryl, P. Rapid change in status: the case of William. *Issues of Mental Health Nursing*. 2005; **26**: 91–99.

Jecker, N.S., Self, D.J. Separating care and cure: An analysis of historical and contemporary images of nursing and medicine. *The Journal of Medicine and Philosophy.* 1991; **16**: 285–306.

Joanna Briggs Institute: http://www.joannabriggs.edu.au. BestPractice, Evidence Based Practice Information Sheets for Health Professionals: Physical Restraint – Part 1: Use in acute and residential care facilities. 2002a; **6(3)**: 1–6.

Joanna Briggs Institute: http://www.joannabriggs.edu.au. *BestPractice, Evidence Based Practice Information Sheets for Health professionals.* Physical Restraint – Part 2: Minimisation in acute and residential care facilities. 2002b; **6(4)**: 1–6.

Juthberg, C., Eriksson, S., Norberg, A., Sundin, K. Perceptions of conscience, stress of conscience and burnout among nursing staff in residential elder care. *Journal of Advanced Nursing*. 2010; **66(8)**: 1708–1718.

Kalis, A., van Delden, J.J., Schermer, M.H. "The good life" for demented persons living in nursing homes. *International Psychogeriatrics*. 2005; **16(4)**: 429–439.

Keady, J. The experience of dementia: A review of the literature and implications for nursing care. *Journal of Clinical Nursing*. 1996; **5(5)**: 275–288.

Kilminster, S.M., Jolly, B.C. Effective supervision in clinical practice settings: a literature review. *Medical Education*. 2000; **34**: 827–840.

Kilstoff, K., Chenoweth, L. New approaches to health and well-being for dementia day-care clients, family carers, and day-care staff. *International Journal of Nursing Practice*. 1998; **4**: 70–83.

Kim, E.J., Buschmann, M.T. The effect of expressive physical touch on patients with dementia. *International Journal of Nursing Studies*. 1999; **36**: 235–243.

Kitwood, T. *Rethinking Ageing Series:* Dementia reconsidered, the person comes first. 1997; Buckingham, UK: Open University Press.

Kolanowski, A.M. An overview of the need-driven dementia-compromised behavior model. *Journal of Gerontological Nursing.* 1999; **25(9)**: 7–9.

Lawton, M.P, Simon, B. The ecology of social relationships in housing for the elderly. *The Gerontologist*. 1968; **8**: 108–115.

Lawton, M.P. The physical environment of the person with Alzheimer's disease. *Aging & Mental Health*. 2001; **5**: 56–64.

Ledger, A.J., Baker, F.A. An investigation of long-term effects of group music therapy on agitation levels of people with Alzheimer's Disease. *Aging & Mental Health*. 2007; **11**: 330–338.

Lin, P.W.K., Chan, W.C., Ng, B.F.L., Lam, L.C.W. Efficacy of aromatherapy (Lavandula angustifolia) as an intervention for agitated behaviors in Chinese older persons with dementia: A cross-over randomized trial. *International Journal of Geriatric Psychiatry*. 2007; **22**: 405–410.

Lutzén, K., Blom, T., Ewalds-Kvist, B., Winch, S. Moral stress, moral climate and moral sensitivity among psychiatric professionals. *Nursing Ethics*. 2010; **17(2)**: 213–224.

Lyketsos, C.G., Colenda, C.C., Beck, C., Blank, K., Doraiswamy, M.P., Kalunian, D.A., Yaffe, K. Task Force of American Association for Geriatric Psychiatry: Position statement of the American Association of Geriatric Psychiatry regarding principles of care for patients with dementia resulting from Alzheimer's disease. *American Journal of Geriatric Psychiatry*. 2006; **14**: 561–72.

Maas, M., Reed, D., Park, M., Specht, J., Schutte, D., Kelley, L., et al. Outcomes of Family Involvement in Care: Intervention for Caregivers of Individuals With Dementia. *Nursing Research.* 2004; **53(2)**: 76–86.

Magai, C., Cohen, C., Gomberg, D., Malatesta, C., Culver, C. Emotional expression during midto late-stage dementia. *International Psychogeriatrics*. 1996; **8**: 383–395.

Martin, B. Restraint Use in Acute and Critical Care Settings: Changing Practice. *American Association of Critical-care Nurses Clinical Issues: Advanced Practice in Acute & Critical Care.* 2002; **13(2)**: 294–306.

McCormack, B. Person-centredness in gerontological nursing: an overview. *International Journal of Older People Nursing*. 2004; **2**: 31–38.

McGilton, K.S., Rivera, T.M., Dawson, P. Can we help persons with dementia find their way in a new environment? *Aging & Mental Health*. 2003; **7**: 363–371.

McMinn, B.G., Hinton, L. Confined to barracks: the effects of indoor confinement on aggressive behavior among inpatients of an acute psychogeriatric unit. *American Journal of Alzheimer's Disease & Other Dementias*. 2000; **15**: 36–41.

Mittelman, M.S., Ferris, S.H., Schulman, E., Steinberg, G., Levin, B. A family intervention to delay nursing home placement of patients with Alzheimer disease. A randomized controlled trial. *Journal of the American Medical Association*. 1996; **276**:1725–31.

Mittelman, M. Psychosocial intervention research: Challenges, strategies and measurement issues. *Aging & Mental Health.* 2008; **12(1)**: 1–4.

Moore, K. Dissonance in the dining room: a study of social interaction in a special care unit. *Qualitative Health Research*. 1999; **9**: 133–155.

Morgan, D.G., Stewart, N.J. Multiple occupancy versus private rooms on dementia care units. *Environment and Behavior.* 1998; **30**: 487–503.

Moyle, W., Edwards, H., Clinton, M. Living with Loss: Dementia and the Family Caregiver. *Australian Journal of Advanced Nursing*. 2002; **19(3)**: 25–31.

Moyle, W., Johnston, A., O'Dwyer, S. Exploring the effect of foot massage on agitated behaviours in older people with dementia: A pilot study. *Australian Journal on Ageing*. 2011; **30(3)**:159–61.

Namazi, K.H., Johnson, B.D. Pertinent autonomy for persons with dementias: modification of the physical environment to enhance independence. *American Journal of Alzheimer's Disease & Other Dementias*. 1992; **7**: 16–21.

Nolan, M., Keady, J., Grant, G. Developing a typology of family care: Implications for nurses and other service providers. *Journal of Advanced Nursing*. 1996; **21**: 356–365.

Nolan, M., Davies, S., Brown, J., Keady, J., Nolan, J. Beyond 'person-centred' care: a new vision for gerontological nursing. *Journal of Clinical Nursing: International Journal of Older People Nursing*. 2004; **13(3)**: 45–53.

O'Connor, D.W., Ames, D., Gardner, B., King, M. Psychosocial treatments of behavioral symptoms in dementia: a systematic review of reports meeting quality standards. *International Psychogeriatrics*. 2009a; **21**: 225–240.

O'Connor, D.W., Ames, D., Gardner, B., King, M. Psychosocial treatments of psychological symptoms in dementia: a systematic review of reports meeting quality standards. *International Psychogeriatrics*. 2009b; **21**: 241–251.

Olazaran, J., Muniz, R., Reisberg, B., Pena-Casanova, J., del Ser, T., Cruz-Jentoft, A.J., Sevilla, C. Benefits of cognitive-motor intervention in MCI and mild to moderate Alzheimer's disease. *Neurology*. 2004; **63**: 2348–2353.

Opie, J., Doyle, C., O'Connor, W. Challenging behaviors in nursing home residents with dementia: A randomized controlled trial of multidisciplinary interventions. *International Journal of Geriatric Psychiatry*. 2002; **17**: 6–13.

Peak, J.S., Cheston, R.I.L. Using simulated presence therapy with people with Dementia. *Aging & Mental Health*. 2002; **6(1)**: 77–81

Pellfolk, T., Gustafson, Y., Bucht, G., Karlsson, S. Effects of a restraint minimization program on staff knowledge, attitudes, and practice: a cluster randomized trial. *Journal of the American Geriatrics Society.* 2010; **58(1)**: 62–69.

Poole, J., Mott, S. Agitated older patients: nurses' perceptions and reality. *International Journal of Nursing Practice*. 2003; **9(5)**: 306–312.

Pusey, H., Richards, D. A systematic review of the effectiveness of psychosocial interventions for carers of people with dementia. *Aging and Mental Health*. 2001; **5(2)**: 107–119.

Raglio, A., Bellelli, G., Traficante, D., Gianotti, M., Ubezio, M.C., Villani, D., et al. Efficacy of music therapy in the treatment of behavioural and psychiatric symptoms of dementia. *Alzheimer's Disease and Associated Disorders*. 2008; **22**: 158–162.

Ragneskog, H., Brane, G., Karlsson, I., Kihlgren, M. Influence of dinner music on food intake and symptoms common in dementia. *Scandinavian Journal of Caring Sciences*. 1996; **10**: 11–17.

Remington, R. Calming music and hand massage with agitated elderly. *Nursing Research*. 2002; **51(5)**: 317–323.

Robin, O., Alaoui-Ismaili, O., Dittmar, A., Vernet-Maury, E. Basic emotions evoked by eugenol odor differ according to the dental experiences. A neurovegetative analysis. *Chemical Sense*. 1999; **24(3)**: 327–335.

Robinson, J., Curry, L., Gruman, C., Porter, C. Partners in Caregiving in a Special Care Environment: Cooperative Communication Between Staff and Families on Dementia Units. *The Gerontologist*. 2007; **47(4)**: 504–515.

Rowe, M., Alfred, D. The effectiveness of slow-stroke massage in diffusing agitated behaviours in individuals with Alzheimer's disease. *Journal of Gerontological Nursing*. 1999; **25**: 22–34.

Royal College of Nursing. 'Let's Talk About Restraint.' *Rights, Risks and Responsibility.* 2008; RCN, London.

Runci, S., Doyle, C., Redman, J. An empirical test of language-relevant interventions for dementia. *International Psychogeriatrics*. 1999; **11**: 301–311.

Sabat, S.R., Harré, R. The construction and deconstruction of self in Alzheimer's disease. *Ageing and Society*. 1992; **12**: 443–461.

Savva, G.M., Zaccai, J., Matthews, F.E., Davidson, J.E., McKeith, I., Brayne, C. Medical Research Council Cognitive Function and Ageing Study: Prevalence, correlates and course of behavioural and psychological symptoms of dementia in the population. *British Journal of Psychiatry*. 2009; **194(3)**: 212–9.

Scherder, E., Bouma, A., Steen, L. Effects of peripheral tactile nerve stimulation on affective behavior of patients with probable Alzheimer's disease. *American Journal of Alzheimer's Disease* & *Other Dementias.* 1998; **13**: 61–68.

Sloane, P.D., Hoeffer, B., Mitchell, C.M., McKenzie, D.A., Barrick, A.L., Rader, J., Koch, G.G. Effect of person-centered showering and the towel bath on bathing-associated aggression, agitation, and discomfort in nursing home persons with dementia: a randomized controlled trial. *Journal of the American Geriatrics Society*. 2004; **52**: 1795–1804.

Sloane, P.D., Raser, J., Barrick, A.L., Hoeffer, B., Dwyer, S., McKenzie, D., Pruitt, T. Bathing persons with dementia. *Gerontologist*. 1995; **35**: 672–678.

Smallwood, J., Brown, R., Coulter, F., Irvine, E., Copland, C. Aromatherapy and behaviour disturbances in dementia: a randomized controlled trial. *International Journal of Geriatric Psychiatry*. 2001; **16**: 1010–1013.

Smith, N.H., Timms, J., Parker, V.G., Reimels, E.M., Hamlin, A. The Impact of Education on the Use of Physical Restraints in the Acute Care Setting. *The Journal of Continuing Education in Nursing*. 2003; **34(1)**: 26.

Snow, A. L., Hovanec, L., Brandt, J. A controlled trial of aromatherapy for agitation in nursing home patients with dementia. *The Journal of Alternative and Complementary Medicine*. 2004; **10(3)**: 431–437.

Snyder, M., Olson, J. Music and hand massage interventions to produce relaxation and reduce aggressive behaviors in cognitively impaired elders: a pilot study. *Clinical Gerontologist*. 1996; **17**: 64–69.

Snyder, M., Egan, E.C., Burns, K.R. Efficacy of hand massage in decreasing agitation behaviors associated with care activities in persons with dementia. *Geriatric Nursing*. 1995a; **Mar/Apr**: 60–63.

Snyder, M., Egan, E.C., Burns, K.R. Interventions for decreasing agitation behaviors in persons with dementia. *Journal of Gerontological Nursing*. 1995b; **21**: 34–40.

Staal, J.A., Sacks, A., Matheis, R., Collier, L., Calia, T., Hanif, H., Kofman, E.S. The effects of snoezelen (Multi-sensory behaviour therapy) and psychiatric care on agitation, apathy, and activities of daily living in dementia patients on a short-term geriatric psychiatric inpatient unit. *International Journal of Psychiatry in Medicine*. 2007; **37**: 357–370.

Standen, M.D., Myers, S.P. The roles of essential oils in the modulation of immune function and inflammation: survey of aromatherapy educators. *International Journal of Aromatherapy*. 2004; **14(4)**: 150–161.

Suhr, J., Anderson, S., Tranel, D. Progressive muscle relaxation in the management of behavioral disturbance in Alzheimer's disease. *Neuropsychological Rehabilitation*. 1999; **9**: 31–44.

Sung, H., Chang, A. M., Abbey, J. The effects of preferred music on agitation of older people with dementia in Taiwan. *International Journal of Geriatric Psychiatry*. 2006; **21**: 999–1000.

Sutherland, J.A., Reakes, J., Bridges, C. Foot acupressure and massage for patients with Alzheimer's disease and related dementias. *Journal of Nursing Scholarship*. 1999; **31**: 347–348.

Svansdottir, H.B., Snaedal, J. Music therapy in moderate and severe dementia of Alzheimer's type: A case-control study. *International Psychogeriatrics*. 2006; **18**: 613–621.

Sörensen, S., Pinquart, M., Duberstein, P. How effective are interventions with caregivers? An updated meta-analysis. *Gerontologist*. 2002; **42(3)**:356–72.

Tadaka, E., Kanagawa, K. A randomized controlled trial of a group care program for community-dwelling elderly people with dementia. *Japan Journal of Nursing Science*. 2004; **1**: 19–25.

Testad, I., Aasland, A.M., Aarsland, D. Prevalence and correlates of disruptive behavior in patients in Norwegian nursing homes. *International Journal of Geriatric Psychiatry*. 2007; **22**: 916-921.

Teri, L., Logsdon, R.G., Peskind, E., Raskind, M., Weiner, M.F., Tractenberg, R.E., Thal, L.J. Treatment of agitation in AD: a randomized, placebo-controlled clinical trial. *Neurology.* 2000; **48**: 442–449.

Thompson, C.A., Spilsbury, K., Hall, J., Birks, Y., Barnes, C., Adamson, J. Systematic review of information and support interventions for caregivers of people with dementia. *BMC Geriatrics*. 2007; **27(7)**: 18.

Tuchtan, C., Tuchtan, V., Stelfox, D. *Foundations of massage* (2nd ed.). 2004; N.S.W.: Churchill Livingstone.

Van Hoof, J., Kort, H.S.M., Duijnstee, M.S.H., Rutten, P.G.S., Hensen, J.L.M. The indoor environment and the integrated design of homes for older people with dementia. *Building and Environment*. 2010; **45**: 1244–1261.

Wells, D.L., Dawson, P., Sidani, S., Craig, D., Pringle, D. Effects of an abilities-focused program of morning care on persons who have dementia and on caregivers. *Journal of the American Geriatrics Society*. 2000; **48**: 442–449.

Wetle, T., Shield, R., Teno, J., Miller, S.C., Welch, L. Family perspectives on end-of-life care experiences in nursing homes. *Gerontologist*. 2005; **45**: 642–650.

Whall, A.L., Black, M.E., Groh, C.G., Yankou, D.J., Kupferschmid, B.J., Foster, N.L. The effect of natural environments upon agitation and aggression in late-stage dementia patients. *American Journal of Alzheimer's Disease & Other Dementias*. 1997; **Sep/Oct**: 216–220.

White, E., Butterworth, T., Bishop, V., Carson, J., Jeacock, J., Clements, A. Clinical supervision: Insider reports of a private world. *Journal of Advanced Nursing*. 1998; **8(1)**: 185–192.

Winstanley, J., White, E. *Clinical Supervision: Models, Measures and Practice: Monograph.* 2002; Sydney: Australian & New Zealand College of Mental Health Nurses Inc.

Witucki, J.M., Twibell, R.S. The effect of sensory stimulation activities on the psychological well-being of patients with advanced Alzheimer's disease. *American Journal of Alzheimer's Disease* & Other Dementias. 1997; **9**: 10–15.

Young, S.H., Muir-Nash, J., Ninos, M. Managing nocturnal wandering behavior. *Journal of Gerontological Nursing*. 1988; **14**: 6–12.

Zeisel, J., Silverstein, N.M., Hyde, J., Levkoff, S., Lawton, M.P., Holmes, W. Environment correlates to behavioral health outcomes in Alzheimer's special care units. *Gerontologist*. 2003; **43**: 697–711.



The IPA Complete Guides to

# **Behavioral and Psychological Symptoms of Dementia**

# Nurses Guide



**BPSD** 

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