

# Managing behavioral and psychological symptoms of dementia- from a geriatrician's perspective.

Dr. Si Ching LIM\*

Department of Geriatric Medicine, Changi General Hospital, Singapore

## Abstract

**As dementia becomes more prevalent, the emergence of behavioral symptoms across the types of dementia causes significant caregiver burden with poor quality of life for the patients with BPSD and contributes to institutionalization. These behavioral symptoms are unpredictable and challenging to manage and as a medical profession, it is frustrating as there is no recommended treatment guideline. Non-pharmacological method is more satisfactory and is as effective as pharmacological means, but it is labor intensive. Pharmacological treatment is associated with significant side effects especially among the frail elderly.**

**Keywords:** Elderly, Dementia, BPSD, Non-pharmacological

Accepted on July 24, 2017

## Introduction

Dementia is an umbrella of progressive neurodegenerative disorders which presents with cognitive symptoms and neuropsychiatric symptoms with progressive decline in function. Neuropsychiatric symptoms, also known as behavioral and psychological symptoms of dementia (BPSD) are difficult to manage, causes caregiver stress and ill health, increases the risk of institutionalization, affects daily function and reduces quality of life [1]. The onset and trajectory course of BPSD is often unpredictable, unlike the cognitive symptoms. This often leaves the caregivers unprepared, leading to resentment and anger towards the persons with dementia (POW). The presence of BPSD also restricts and limits the caregivers' personal time and social life which contribute to caregiver stress resulting in anxiety and depression [2]. The presence of BPSD is also associated with more rapid disease progression, accelerates functional decline, reduces quality of life and has been associated with early nursing home placement and the usage of restraints.

This paper reviews the commoner symptoms of BPSD in dementia, the etiology of behavioral changes and ways to manage BPSD non-pharmacologically. There is a short mention of mild behavioral impairment which is the presence of neuropsychiatric symptoms in the prodromal stages of dementia, its implications and prognosis.

## Mild Behavioral Impairment

Neuropsychiatric symptoms are often present in the mild cognitive impairment (MCI) stage which is considered as the prodrome of dementia. In a study by Feldman, it was reported that 59% of patients with MCI have neuropsychiatric symptoms, and compared to the patients without neuropsychiatric symptoms, those with positive symptoms showed greater MCI severity with impairment in the global, cognitive and functional scores. The presence of NPS in patients with MCI increases risk of progression towards dementia, with an annual conversion rate of 25% [3,4]. Even among healthy elderly with no cognitive

complaints, the presence of agitation, apathy, anxiety, irritability or depression increases the risk of developing MCI [5].

Although behavioral symptoms are commoner among the behavioral variant of front temporal dementia (FTD), patients who presented with NPS in advance of cognitive complaints may eventually developed into FTD, Alzheimer Disease (AD), vascular dementia (VaD) and other types of dementia at follow up [6].

The International Society to Advance Alzheimer's Research and Treatment (ISTAART) diagnostic criteria for MBI requires that changes in behavior or personality to be starting in late life (>50), persisting for  $\geq 6$  months, and is a change from the patient's usual behavior and personality. The behavioral changes are of sufficient severity to cause interference with interpersonal relationships or affect social/ vocational functioning. The patient does not qualify for diagnosis of dementia and the changes in behavior or personality is not due to another psychiatric disorder. MCI can be present, but is not a requirement. MBI has been broken down into 5 domains- affective disorders, motivation, social cognition, impulse control and perception/ thought content [7]. Clinically, it is acceptable to use neuropsychiatric inventory (NPI) to monitor NPS in MCI and dementia [7].

## Spectrum of BPSD

It is useful to classify BPPSD into behavioral or psychological symptoms (Table 1) for treatment purposes, especially if pharmacotherapy is being considered. Some of the commoner BPSD will be discussed below.

### Aggression

Aggression is referred to as "an overt act, which involves delivery of noxious stimuli to (not necessarily aimed at) another object, self or organism, which is clearly not accidental" [8]. The aggressive behaviors can be either physical (biting, hitting, spitting, throwing objects, etc.) or verbal (swearing, cursing, shouting, etc.). Aggressive behaviors are well recognized to

cause caregiver stress, increase caregiver burden, psychotropic medication use and risk of institutionalization [9]. Aggression commonly co-occurs with agitation among the POW, and caregiver frustration is greater when there is a combination of behavioral symptoms. The caregivers who express their frustrations towards the POW will further exacerbate the aggressive behaviors giving rise to a vicious cycle of abusive communication [10,11].

Aggression also includes sexual disinhibition. Sexual disinhibition can either be sex talk or sex acts which manifest as use of inappropriate language which is not usual for the patient's premorbid personality, touching, grabbing, exposure of genitalia, masturbating in public or private. Sexual disinhibition has been reported in AD, VaD, MCI and more commonly in FTD. Sexual disinhibition is commoner among men than women and has been reported across all stages of dementia severity.

Sexuality is expressed very differently across different cultures and societies and it is therefore difficult to define what constitutes an appropriate behaviour. Assessment of appropriateness of behaviour is subjective, according to the observer's approving/ disapproving attitudes, rather than the behaviour per se. Also, clinicians ought to take into account that sexual desire and libido is still present well into the old age and the inappropriate behaviour may surface due to a lack of willing sexual partner or privacy especially among the institutionalized elderly. Sexual disinhibition can be extremely disturbing to the caregivers, with reports of anxiety, embarrassment and feeling of unease among the caregivers and may result in legal actions [12,13].

### ***Depression and dementia***

The relationship between depression and dementia is a complex one. There is now good evidence to suggest that late life onset of depression is a risk factor for dementia. Depression is also thought to be the prodromal stage of dementia. The evidence also suggests that depression co-occurring in the stage of MCI increases the risk of progression to dementia [14-19].

Depression is common in all stages of dementia. It is estimated to be present in 20-30% of patients with AD and similar percentage across the stages of AD. In VaD, the incidence may be higher, 40-45%. Making a diagnosis of depression among the elderly with dementia is often difficult due to the atypical presentations, poor insight and the diagnosis can be influenced by the caregivers' reaction and mood disorder [20].

The symptoms of depression among the elderly differ from the younger patients with depression. The elderly with depression are more likely to complain of not feeling well, lack of pleasure or lack of emotional response, rather than complaining of feeling sad or low mood. Among the elderly with AD and depression, they present with even more atypical features of depression, such as irritability, worry, anxiety or fear. They may have mood disturbances with short episodes of sadness which lasts for minutes but frequently recurring within a time frame of few hours. They are more likely to show poor motivation, low self-esteem, lack of interests in activities which they previously enjoyed with gradual withdrawal, socially isolating themselves

and talk less. They have difficulties persisting with activities and even getting out of their beds to start the day is hard. Biological symptoms typically involve poor appetite with weight loss, difficulties falling and staying sleep. The depressed elderly with dementia tend to exhibit less guilt or suicidal thoughts. Among the depressed elderly with dementia, psychotic symptoms may be prominent, compared to the non-demented elderly, with vague persecutory delusions, suspiciousness and fear and this makes treatment decisions more challenging for the clinicians [21,22].

Depression among the elderly with dementia carries with it negative outcome for the caregivers as well as the POW. For the elderly persons with dementia, depression causes weight loss, frailty, mental suffering, disabilities requiring assistance with ADLs and are more likely to be institutionalized. Their caregivers are more likely to develop depression with higher caregiver burden [21,23].

### ***Apathy***

Apathy is persistent loss of initiative and motivation with goal directed behavior and causes functional impairment. Apathy is the commonest behavioral symptom of AD, reported in up to 76% of patients with AD and other types of dementia such as behavior variant FTD, Parkinson's Disease dementia and VaD. Apathy in AD is associated with higher disease burden resulting in faster decline of cognition, function, emotional impairment and depression. Apathy in AD is also thought to be associated with more severe behavioral symptoms [24,25].

Symptoms of apathy consist of emotional blunting and lack of engagement to negative or positive events, lack of interest, lack of motivation/ effort to perform daily activities, dependency on others to plan or structure activities and lack of concern for one's problems. Assessment of apathy is challenging among the patients with dementia, where lack of motivation may be due to poor cognition and therefore loss of ability. Depression shares symptomology with apathy, and frequently, psychotropic medications used in the management of BPSD cause lethargy, reduced responses, emotional blunting and fatigue which can mimic apathy [26].

### ***Psychotic symptoms of dementia***

The POW often misinterprets or misunderstands stimuli and reality because of their sensory impairment and their failing cognition. The common psychotic symptoms in BPSD include hallucination and delusions. The psychotic symptoms vary in quality and nature compared to schizophrenia. Hallucinations tend to be visual in dementia. The symptoms more commonly seen are discussed below [27].

People stealing their properties are common complaints both in institutions and in the home environment. The POW is more likely to have misplaced or forgotten where they hid their properties, and they end up accusing their caregivers or fellow residents of stealing their properties.

They may accuse their spouses of infidelity. This occurs when the POW is placed in an institution or when there is another caregiver who interacts regularly with their spouse. This may be due to feeling of abandonment, loss of trust or betrayal when

they are placed in an institution. With the presence of a caregiver in their home setting, they may feel the loss of their roles in their own household and the chores they used to do is being taken over by someone else, creating a false belief that they spouses had them replaced.

They may misidentify their caregivers as imposters and refuse to cooperate with ADLs when assisted. This is frequent in a hospital and nursing home setting. Due to their failing memory, they are unable to remember faces or name, this is contributed by frequent turnover of staff in an institution. It is advisable for the caregivers to introduce themselves every time they come in contact with the person with dementia.

Sometimes the POW is unable to recognize their own image on the mirrors. This too, may give rise to the accusation of imposters being present in their house and cause them fear and agitation every time they walk past a mirror.

The elderly POW with hearing and visual impairment may misinterpret stimuli or misidentify objects especially in a new environment. Announcements coming through the public announcement system may be perceived as alien communications.

**Appetite and eating disorders in dementia**

Eating is essential to life and POW develop a variety of eating disorders such as difficulties with eating, chewing, swallowing, changes in food preference and appetite changes. Caregivers’ worries of insufficient intake of food increase caregiver burden and diminish patients’ quality of life, with excessive watchfulness and pressure to eat at mealtimes. In an institution, feeding times are rigid and there may be insufficient trained staff to supervise residents during feeding time causing malnutrition and weight loss.

Eating disorders are commoner among the FTD. Some of the well documented eating disorders among the FTD and semantic dementia are problems with hyperorality, changes in eating habits, food preference for sweet foods, wanting the same food over and over and dysphagia as late feature in semantic dementia [28].

For patients with AD, changes in appetite and food preference occur with corresponding changes in body weight. The changes in appetite may be due to concurrent presence of depression and the increase in appetite maybe due to amnesia such that the POW forgotten they have eaten and ask for meal again. In the late stages of AD, swallowing difficulty is the main

concern. The diet is often modified in consistencies to suit the various degree of swallowing impairment. These modified diets may interfere with the presentation and taste of the food. Drugs used for treatment of AD or BPSD may have effects on the appetite [29].

Towards the severe stages of dementia, the POW often have swallowing disorders, anorexia and feeding times are prolonged and challenging to the caregivers. Tube feeding is generally avoided as it has not been shown to improve outcome, prolong survival or reduce complications [30,31].

**Sleep disorders and dementia**

Sleep architecture changes with ageing, with less time spent in the Rapid Eye Movement (REM) stage and a higher proportion of time spent in stages 1 and 2 sleep. Up to 40% of patients with AD have some form of sleep disorders. Among the common sleep disturbances in AD are frequent awakenings in the night, with longer periods of wakefulness, sleep fragmentation, day time sleepiness and these changes in sleep patterns cause caregiver fatigue and stress. Sleep disorders among AD have been associated with BPSD symptoms like irritability, aggression, anxiety, high falls risk and poor cognitive performance during the day. Sleep disorders have been associated with higher risk for dementia, particularly REM sleep disorders which increases risk of DLBD [32,33].

For management of sleep disorders among the patients with dementia, the first line should be environmental and behavioural approach, with practice of good sleep hygiene as shown in table 2 [34]. Pharmacological means should be limited because of the adverse events associated with sedation and hang over effects. It is recommended to start with short acting benzodiazepines, non-benzodiazepine hypnotics and melatonin for short duration, at the lowest effective dose. The increased falls risk and sedation must be weighed against effectiveness [35].

**Management Strategies for BPSD**

For a Geriatrician’s perspective, the first line management of choice for BPSD should be the non-pharmacological approach. This is because there are currently no clear treatment guidelines or recommendations for managing the various symptoms of BPSD and the drugs used in the management of BPSD are often associated with side effects which are undesirable for the elderly. The elderly patients frequently have a long list of comorbidities and are on a long list of medications thus increasing the risk of drug drug interactions and drug toxicity.

*Table 1. Spectrum of BPSD.*

Behavioral	Psychological
<ul style="list-style-type: none"> <li>• Physically aggressive- biting, pinching, agitation, scratching, sexual disinhibition.</li> <li>• Physically non-aggressive- wandering, stripping, hoarding, pacing, blank stares, urinating/defecating in inappropriate places.</li> <li>• Verbally aggressive- swearing, cursing, shouting, threats, screaming.</li> <li>• Verbally nonaggressive- repetition, calling for attention.</li> </ul>	<ul style="list-style-type: none"> <li>• Personality change</li> <li>• Anxiety</li> <li>• Depression</li> <li>• Pathological crying</li> <li>• Mood lability</li> <li>• Hallucinations- visual/ auditory</li> <li>• Delusions</li> <li>• Apathy</li> <li>• Elevated mood</li> <li>• Sleep disorders</li> </ul>

Among the commoner side effects seen in the elderly include sedation (benzodiazepines, antipsychotics, SSRI, mood stabilizers), extrapyramidal side effects (antipsychotics, SSRIs, mood stabilisers) liver toxicity especially with mood stabilizers, and cardiac toxicity with antipsychotics.

In order to plan for non-pharmacological strategies for managing BPSD, it is useful to understand the aetiologies of the various behavioral symptoms and manage any reversible causes of BPSD.

**Understanding BPSD**

BPSD is diverse, widely heterogeneous and the symptoms fluctuate with time. Little is known about the exact aetiology. Cohen-Mansfield put forward the theory of unmet needs, vulnerability to environmental stresses with reduced ability to cope and lastly, a learned behavioural pattern to understand the causes of challenging behaviours among the POW [36,37]. BPSD is frequently labeled as challenging behaviours in institutions as it is challenging and frustrating for the staff to manage an elderly with BPSD. However, these challenging behaviours should be viewed as a means to communicate with the caregivers, as the usual way of using verbal communication fails in dementia as cognition worsens. The theoretical model is helpful for analyzing behavioural symptoms in dementia and in forming strategies for management of BPSD non-pharmacologically.

Among the persons with dementia, as cognition worsens, the ability to communicate their needs verbally declines. This gives rise to increasing agitation as their caregivers are not aware of their needs and are not able to fulfill them. The unmet needs cause discomfort and anxiety which eventually results in the emergence of challenging behaviours. Measures to preempt and manage these needs require staff and caregiver education and training. Among the common unmet needs giving rise to challenging behaviours are listed in Table 3. These unmet needs are generally manageable and if the caregivers can preempt and

put in steps to reduce anxiety and discomfort, it is rewarding for the caregivers as well as the POW (Table 3).

The elderly with dementia are also less tolerant to changes in their environment. As their cognition worsen, their threshold for reacting to stresses lower and their abilities to cope reduces. The stressful environment, which may be too cold / hot, too noisy / quiet, or under-stimulating often gives rise to anxiety and challenging behaviours. A calm environment with a fixed and structured routine and minimum change in care staff is less demanding for the POW.

The learned behavioural model uses the ABC of behaviour to understand the emergence of certain pattern of behaviour in an individual. Behavioural analysis (ABC model of behaviour) starts with looking at the antecedent events, often the stimuli leading to the problem behaviour. After the emergence of the behaviour, there is a need to observe the consequences of the behaviour. The consequences usually involve attention obtained as a result of the abnormal behaviour. The consequences reinforce certain behaviours in response to the stimuli. Therefore, in order to change the individual's behaviour, he/ she needs to relearn the appropriate response to a stimulus.

**Personhood**

In care institutions like nursing homes and hospitals, Tom Kitwood introduced the concept of personhood while caring for the POW [38]. According to Kitwood, personhood is defined as “a standing status bestowed upon one human being, by others, it implies recognition, respect and trust”. The personhood of any individuals can be enhanced resulting in a state of wellbeing with recognition, respect and trust. Caregiver's or staffs' behaviours and actions which enhance a person's wellbeing are grouped under positive person work. Conversely, when personhood is undermined by staff's actions or behaviours (malignant social psychology), it results in a state of illbeing. Malignant social psychology arises because staffs/ caregivers are often unaware of the needs and disabilities faced by the POW, hence they are

**Table 2. Sleep hygiene.**

Good habits	Bad habits
Regular sleep pattern and ritual with same bed time and rise time.	Frequent napping during day time. Avoid naps >30 min duration and no naps after 4pm.
Go to bed only when you are sleepy	Heavy meals late and close to bed time
If you are unable to fall asleep, get out of bed to do other activities, return to bed when you are sleepy.	Avoid prolonged periods of rest in beds and doing daytime activities in bed like watching TV or reading.
Bed room environment is conducive to sleep-lighting, sound and temperature.	Avoid stimulants like caffeine, smoking and alcohol in the afternoons.
Use the bedroom only for sleep purposes.	Strenuous exercises 2 hours before bedtime.
Sufficient light exposure and activities during the day	Stimulating activities like gaming prior to bedtime.

**Table 3. Causes of agitation among elderly with dementia.**

Pain- inadequately treated
Restraint use- limits autonomy of movement, both physical and chemical restraints may worsen agitation
Delirium- particularly if the change in behavior is a new feature.
Physiological needs- hunger, thirst, and feeling tired.
Social reasons- boredom, loneliness, changes in routines or caregivers.
Elimination- Urinary retention, constipation.
Drugs- antipsychotics, drugs with anticholinergic side effects.
Environment- new changes, too warm/ cold, an under or overstimulated environment.
Sensory- sensory impairment like visual/ hearing impairment, misinterpretation of stimuli.
Emotional needs- anxiety, boredom, feeling frightened, insecure, etc.

often not acknowledged in society and are treated poorly as a result. Malignant social psychology arises because of lack of education in most cases, rather than inflicted on purpose.

The emergence of challenging behaviours differs among the persons with dementia. The theory behind this takes into account an individual's premorbid personality, past experience, medical conditions with its deficits and social psychology. Person centred care is therefore about understanding the triggers for the challenging behaviour and find ways to plan care for each individual differently to promote one's personhood.

In an institution, the advocate for person centred care has been shown to bring about the state of wellbeing, and less emergence of challenging behaviour. Dementia care mapping is usually carried out in an institution setting where a trained mapper is seated ambiguously to observe the behavioural pattern of the residents as they interact and communicate with the staff/ caregivers over a period of time. Each session of mapping can take up to several hours. The result of mapping is then analysed and intervention plans are put forward to improve staff's behaviour and attitude towards the patients/ residents. The care staffs are educated on the various behavioural patterns displayed by the POW as a result of how they are treated. Staffs' behaviours which enhances the POW's wellbeing are encouraged. Conversely, staffs' attitudes or actions which trigger an outburst of challenging behaviour or causes illbeing are discouraged. Care staffs are educated to observe for behaviours like crying, withdrawal and negative mood which indicate illbeing, when personhood is undermined [38].

### **Non-pharmacological Management of BPSD**

This approach aims at addressing the psychosocial and environmental causes of behavioural symptoms. This approach also avoids medication side effects and drug-drug interactions especially since medications have not been well proven to be efficacious. Medication use, when effective, causes sedation which may mask the underlying unmet needs even further [37].

The non-pharmacological approach to management of BPSD starts with general measures like interviewing the caregivers for a detailed account of the behavioural symptoms, its triggers and impact on caregivers. Caregiver education and support are important to manage their expectations and help them understand that behaviours are not intentional and find ways to improve communication and create meaningful activities to keep the patients occupied [39]. More targeted approach includes ways to solve specific problematic behaviour such as depression, sleep disorders, pain management, etc. The targeted approach emphasises more on listening to the non-verbal means of communications from the POW's perspective. Activities need to be reexamined and redesigned, as unsuitable activities may create demands and stress for the POW and the frustrations may give rise to challenging behaviours. Environmental adjustment like lighting, noise level, sleep environment may be helpful as well [40].

Non-pharmacological interventions include:

- Sensory stimulation- shiatsu, aromatherapy, acupuncture, massage, light therapy.
- Cognitive stimulation- music therapy, dance therapy, snoezelen.
- Cognitive/ emotion stimulating- reminiscence, validation and simulated presence therapy.
- Others- pet therapy, sensory room, exercise therapy.

Most of the data available to date on the non-pharmacological interventions are inconsistent, because the patients were heterogeneous; the types of dementia were mixed as well as the stages of dementia. Music therapy reduces anxiety but evidence is not strong. Massage and aromatherapy both showed conflicting results. Light therapy failed to show significant effect. Trials on validation and reminiscence therapies did not show statistically significant improvement, with trials of small sample size and short duration to reach significant difference.

Caregiver training and dementia care mapping, supervised by healthcare professionals were found to be effective in reducing agitation and persisted for 3-6 months. Exercise and pet therapy also failed to show positive effects on managing BPSD [41].

### **Pharmacological Management of BPSD**

The drugs commonly used for managing BPSD include antipsychotics, antidepressants, antiepileptics such as valproate and carbamazepine as mood stabilizers, benzodiazepines, cholinesterase inhibitors and N-methyl-D-aspartate-receptor modulator. There is no clear standard recommendation and the usage is often based on individual preference. Drug treatment is often not effective in symptom control. The trials are difficult to interpret because of the modest improvement in the various scales used and difficult to translate into clinically meaningful outcomes.

#### ***Antipsychotics***

The older typical antipsychotics showed benefit in management of aggression with haloperidol but the benefit is masked by serious side effects which are mainly the extrapyramidal side effects. There is no difference in effectiveness between different typical antipsychotics.

The newer atypical antipsychotics include Risperidone, Quetiapine, Olanzapine, Clozapine and Aripiprazole. Both Olanzapine and Risperidone have clear benefits in aggression, agitation, delusion and hallucination. The risk of extrapyramidal side effects are lower compared to the older antipsychotics but somnolence is problematic and stroke risk was three times higher than placebo. There is now a FDA black box warning for using antipsychotics in treating elderly with BPSD [42].

#### ***Antidepressants***

As a group, SSRI are well tolerated and useful for the treatment of depression, but not beneficial in managing the other BPSD [43].

### **Mood stabilisers**

Valproate does not appear to be effective in treatment of BPSD and is associated with sedation [44]. Carbamazepine has a black box warning for haematological toxicity and has not been shown to be effective in managing BPSD. Therefore, there is no evidence to support use of either in management of BPSD [42].

### **Cholinesterase inhibitors**

Some trials showed statistical significant benefit in the management of BPSD, but the effects are modest [4,45].

### **N-Methyl-D-aspartate receptor modulator**

Meantime may be of benefit in cognition and function in a trial which showed meantime with a decrease in NPI score compared to placebo who showed a decline of 3.7 points. However, the improvement in the NPI score was modest [45].

### **Conclusion**

The spectrum of BPSD is wide and the symptoms fluctuate from time to time and there is no single solution for managing BPSD. It is important to ask about BPSD with the caregivers regularly and intervene before caregiver burnout occurs with education, creating meaningful activities, psychosocial and environmental manipulations. Pharmacological management should be second line management strategy and should be reviewed at regular intervals with an attempt to reduce and remove once the behavior improves since the risks of adverse events are high.

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**\*Correspondence to:**

Dr. Si Ching LIM  
 Senior Consultant  
 Department of Geriatric Medicine  
 Changi General Hospital  
 Singapore  
 Tel: +65 91131404  
 E-mail: si\_ching\_lim@cgh.com.sg