UNIT NO. 1

BEHAVIOURAL AND PSYCHOLOGICAL SYMPTOMS OF DEMENTIA – ASSESSMENT AND MANAGEMENT

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ABSTRACT

Behavioural and psychological symptoms of dementia (BPSD) are defined as signs and symptoms of disturbed perception, thought content, mood or behaviour. BPSD are very common regardless of the type of dementia and is present in nearly all people with dementia over the course of their illness. A local study conducted in 2013 found the prevalence of BPSD amongst the study population suffering from dementia to be 67.9 percent. BSPD are associated with major adverse effects on daily function and quality of life; significant financial cost, higher use of healthcare facilities; and premature institutionalization. Effective assessment and management of BPSD involves the understanding of how the interplay of various factors (persons with dementia, caregivers, and environment) may cause BPSD and that interventions must be tailored to each individual. The first line of management should always be non-pharmacological interventions where possible. The ultimate goal in treatment of BPSD is to alleviate suffering, reduce caregiver burden and lower societal costs in persons with dementia.

Keywords: Dementia; Behavioural and psychological symptoms of dementia; Neuropsychiatric symptoms of dementia; Person-centred care; Treatment of dementia; Management of dementia

INTRODUCTION

Dementia is estimated to affect 50 million people worldwide in 2018, and this number is expected to reach 82 million by 2030 and 152 million by 2050.[1] The prevalence of dementia is on a rising trend with the rapidly aging population in Singapore. There were about 40,000 persons with dementia here in 2015, and this is projected to reach 53,000 by 2020, and 187,000 by 2050. The Well-Being of the Singapore Elderly (WiSE) Study conducted in 2013 found that the prevalence of dementia was 10 percent in those aged 60 years and above.[2] The WiSE Study also found that the annual cost per person suffering from dementia was estimated at S$10,245 per year. As a country, the total cost of dementia in 2013 was estimated at S$532million.[3] To tackle the serious and growing problem of dementia in Singapore, dementia-friendly towns are being developed, elder day-care capacity and nursing home beds are being increased and dementia-specific training for caregivers is being developed. However, until these measures are in place, the burden has fallen on informal caregivers such as family members and foreign domestic workers to look after people with dementia in their homes and the community.

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Behavioural and psychological symptoms of dementia (BPSD), also known as neuropsychiatric symptoms of dementia, represent a heterogenous group of non-cognitive symptoms and behaviours occurring in persons with dementia.[4] BPSD are defined as signs and symptoms of disturbed perception, thought content, mood or behaviour.[5] BPSD are very common regardless of the type of dementia and present in nearly all people with dementia over the course of their illness. A local study conducted in 2013 found the prevalence of BPSD amongst the study population suffering from dementia was 67.9 percent.[6] BSPD are associated with major adverse effects on daily function and quality of life; significant financial cost, higher use of healthcare facilities; and premature institutionalisation. Most people with dementia are cared for by informal caregivers and BPSD is strongly associated with stress and depression in carers, reduced income from employment and lower quality of life.[7] It is therefore imperative to identify BPSD and reduce the impact of these symptoms on the people with dementia as well as their caregivers.

Types of Behavioural and Psychological Symptoms of Dementia

The clinical presentation has a wide variation and there are many ways in which BPSD can be grouped for ease of identification and management. Table 1 details various BPSD grouped into symptom clusters that include disturbances of emotional experience, delusions, perceptual disturbances, disturbances in motor function, disturbances in circadian rhythm, and changes in appetite and eating behaviour.[4,7] These symptoms are somewhat universal regardless of the etiology of dementia, but some types of dementia are more commonly associated with certain behaviours. For example, depression is more frequent in vascular dementia; visual hallucinations are common in Lewy Body Dementia; and executive dysfunction, disinhibition and apathy are more often exhibited in frontotemporal dementia.[8,9]

BPSD can be present across all stages of dementia, although their type and prominence depend on the stage. For example, anxiety and depression are more commonly seen in the early stage of Alzheimer's disease and may worsen with illness progression. Agitation is common, persistent and may increase with disease severity. Apathy is commonly reported by family members across all stages of dementia and may worsen over time. Delusions, hallucinations, and aggression are more episodic and more common in the moderate to severe stages of disease.[10-14]

Causes of Behavioural and Psychological Symptoms of Dementia

BPSD cannot solely be explained by cognitive decline, there are various contributory factors that have been identified, including persons with dementia factors, caregiver factors and environmental factors.

Factors related to the person with dementia
Neurobiology: Structural and functional neuroimaging and biomarker investigations have provided a better understanding of the neurobiological basis of BSPD. For example, the circuit model theorizes that various synaptic or circuit disconnections which mediate planning, organization, executive function, motivated behaviour inhibitory control could result in BPSD. The ascending monoaminergic system also has a role to play, as serotonin, norepinephrine and dopamine mediate behaviour, mood and psychosis.[15,16] Disruptions in circadian rhythms can result in BPSD and lead to agitation during the day, restlessness at night and contribute to sundowning.[17]

Acute medical conditions: Undetected or undiagnosed illness can lead to delirium that are associated with BPSD that include agitation, crying out, delusions and hallucinations. Common medical conditions that are associated with BPSD include pain, infections, urinary retention, constipation and side effect from drugs.[18,19]

Unmet needs: Persons with dementia may have a loss of ability to adequately verbally express their needs or goals, leading them to communicate and express needs through various behaviours. BPSD can be seen as the person's ineffective attempt to cope with physiological or environmental stress factors. The lack of meaningful activity or engagement may also develop into unmet needs.[20,21]

Pre-existing personality and psychiatric illnesses: Long standing personality patterns and characteristics may have a role in the development of BPSD, as the loss of inhibitory control may accentuate premorbid personality traits. A person's most distinctive features are likely to play a role in how someone with dementia copes with their increasing deficiencies. For example, persons with suspicious, aggressive or controlling premorbid personality traits are more likely to develop BPSD subsequently.[22] Long standing psychiatric disorders such as major depression, anxiety disorders, bipolar disorder and schizophrenia, as well as their psychotropic treatment can also affect the development of BPSD.

Factors related to caregivers
Caregivers are more likely to experience stress and suffer from depression when managing persons with BPSD.[23] In turn, caregiver distress and poor interpersonal interactions between the person with dementia and the caregiver can exacerbate BPSD.[24] Caregivers' coping abilities and strategies, use of negative communication styles (e.g. anger, shouting, hostility), and disparity between caregiver expectations and the stage of dementia can trigger or aggravate symptoms.[7] Caregiver stress, insight, depression and culture, amongst many factors, can affect how they report symptoms to healthcare professionals and how they carry out treatment recommendations.[25,26]

Factors related to environmental triggers
Persons with dementia are sensitive to change in their physical and social environment. As the cognitive impairment progresses, there is increasing difficulty with processing and responding to environmental stimuli. Change in routine, over or under stimulation, physical and social environmental changes, and demands that exceed functional ability can cause stress. This can lead to a decreased stress threshold of the person with dementia, and the potential for frustration increases, resulting in anxiety, depression or agitation.[27,28]

Assessment of Behavioural and Psychological symptoms of Dementia

A well informed BPSD assessment begins with a systematic approach that involves a detailed history including direct patient interview and multiple informants, a review of medical records, and focused physical, neurological and mental statusexaminations.[29]

History obtained from the patients themselves could be subjective and tinted with recollection bias or limited insight. History obtained from the caregiver can be more objective but it may be coloured by their relationship with the patient and needs to be provided by someone with good knowledge of the patient's daily life. As such, there are a variety of scales and tools to help document BPSD such as the Cohen-Mansfield Agitation Inventory[30] and the behavioural pathology of Alzheimer's disease (BEHAVE-AD)[31], but these are infrequently used in the clinical setting to guide management.[32] The short version of the Neuropsychiatric Inventory, the NPI-Q[33], is most often used due to its ease of administration and comprehensiveness.

A review of the medical history including the medication list is also prudent. A physical examination should be performed to identify and exclude possible underlying and modifiable medical causes. A neurological examination should look for perceptual deficits such as hearing and visual loss, as well any functional disability. A cognitive assessment should be done to evaluate the patient's cognitive impairments, such as short-term memory and dysphasia.

With regards to the individual symptoms, it is important to identify the timing, frequency, severity and diurnal variation. It is also helpful to ascertain antecedents to the challenging behaviour, such as psychosocial and environmental triggers, and any other factors that may perpetuate the BPSD. Finally, the impact of the BPSD on the patient and the caregiver needs to be determined.[34]

Management of Behavioural and Psychological symptoms of Dementia

Due to the complex etiology of BPSD, a "one size fits all" solution does not exist. Management involves thinking beyond person centred care to incorporate the unique role of caregivers, be

those family members or professionals' carers.[7]

Non-pharmacological interventions

Prior to initiation of any intervention, it is critical to rule and treat any potential medical causes of BPSD. In the absence of a treatable condition, non-pharmacological strategies are the first line of treatment to manage the milder BPSD. For moderate to severe BSPD, medication can be used as an adjunct to non-pharmacological interventions. Behavioural approaches should address the cause of the symptom and its relation to the experience of the person with dementia; resolve or minimize challenges and obstacles to the patient's comfort, security and easy of mind; and be given a sufficient trial before initiating pharmacotherapy.[35] There may be a need to continually modify and adapt solutions to the symptoms, as intervention must be tailored to the individual to be most effective.

Interventions targeting the person with dementia

In the person-centred care approach, caregivers are encouraged to see the individual as a whole, and see beyond the disease; place emphasis on their remaining cognitive and emotional abilities; and focus on the individual's life experience, unique personality and network of relationships.[36]

Reality orientation is a widely used management approach to help with memory loss and disorientation by reminding persons with dementia of the facts about themselves and their environment. Consistent use of orientation devices such as signposts, notices and other memory aids can reduce confusion.[37]

There is a vast array of interventions for reducing symptoms by increasing levels of well-being, providing pleasure and cognitive stimulation:

Emotion oriented therapies

- Reminiscence therapy – Discussing past experiences, especially those that are positive and personally significant
- Validation therapy – Empathizing with the feelings and meanings hidden behind confused speech and behaviour, working through unresolved conflicts
- Simulated presence therapy – Use of audio recordings of family members to provide familiarity in the environment

Sensory stimulation therapies

- Aromatherapy – Use of fragrant plant oils to soothe or stimulate
- Music therapy – Playing music, singing, moving or dancing to music for stimulation and engagement
- Snoezelen multi sensory stimulation – Placing the person with dementia in a soothing and stimulating environment
- Acupuncture – Improves mood and cognition, increases verbal and motor skills
- Light therapy – Seen to help regulate the circadian rhythm, improve sleep patterns and reduce agitation[7,37]

Psychological interventions including psychotherapy, cognitive training and rehabilitation can be useful, particularly in the early stages of dementia. Many persons with dementia need help structuring their lives as they give up previous activities and become acquainted with activities they still have the cognitive capacity to perform. They may also need help acknowledging the fear of their cognitive losses, and the anxiety involved in the exposure to social situations or the adjustment to a reduction in their social life.

Interventions for family caregivers

In working with caregivers, the goal is problem solving to identify precipitating and modifiable causes of symptoms. One of the most widely used approaches is known as the ABC (antecedent, behaviour, consequence) method. Using a chart or a diary is a good way to gather information about the manifestations of a behaviour. By understanding the sequence of events leading up to and following the behaviour, interventions can then be prescribed based on the analysis of these findings.

Caregivers may also benefit from caregiver training, support groups or family therapy. Caregivers need help accepting the diagnosis, accepting role changes and the increasing dependence of the person with dementia. As the illness progresses, the caregiver may need help in the grieving process of the loss of the person with dementia. They may also need a lot of encouragement and validation to take care of their own well-being without feeling guilty. They may require additional services from social workers or community services for elder sitters, day care services, respite placements or financial assistance.

Interventions to improve the environment

The ideal environment for a person with dementia is one that is non-stressful, constant and familiar. Persons with dementia thrive best in environments that are not over- or understimulating to the senses. In the physical environment, the use of soft lighting and calm colours are soothing and carpets can absorb sound. On the contrary, abstract or noisy designs, mirrors, and loud telephone ringing can be confusing or frightening. Provisions need to be made to provide a safe environment. Some considerations include restriction of access to household chemicals or sharp objects; accessibility to areas for ambulation and exits around the home should be modified if necessary; and GPS trackers for those who are still community ambulant but at risk of losing their way. The Alzheimer's Disease Association offers a Safe Return Card programme to address wandering issues. An established routine with regular activities that match the interests and capabilities of the individual can reduce stress and agitation. Changes in routine should be as gradual as possible, so as to allow individuals time to familiarize and habitualize to the alterations.[38] Sleep disturbance is common and one of the most distressing symptoms. Good sleep hygiene should be promoted, and involves a structured routine to increase daytime physical activity and minimize naps; avoidance of stimulants such as caffeine; a conducive sleeping environment with minimal noise and a dark bedroom; and relaxation before bedtime such as taking a warm bath or listening to soothing music.[39]

Pharmacological Interventions

Pharmacological treatment for BPSD should only be considered if the symptoms cannot be attributed to a physical cause; has not responded to non-pharmacological interventions and the symptoms cause significant distress or risk to the person with dementia. There is limited evidence to support the use of drugs in the management of BPSD, and it must be noted that most of

the commonly used drugs are not approved for use.

The MOH Clinical Practice Guidelines on Dementia provides a treatment algorithm that is easy to follow:[40]

- Antidepressants can be used for the treatment of depression and anxiety symptoms. Commonly used drugs include selective serotonin re-uptake inhibitors such as fluvoxamine and escitalopram, or noradrenergic and specific serotonergic antidepressant like mirtazapine. Serum sodium must be monitored as syndrome of inappropriate antidiuretic hormone secretion is a possible side effect.
- Sodium valproate, a mood stabilizer, can be used to manage mood lability. Although there is no evidence to demonstrate its benefits in management of agitation, [41] anecdotally, it has found to be useful at times in the local clinical setting.
- Atypical antipsychotics, such as risperidone, olanzapine and quetiapine are evidenced to be useful for the treatment of severe psychosis and aggression or if unresponsive to other drugs.[42, 43]Possible side effects include sedation, increased risk of falls, metabolic syndrome and extra pyramidal side effects. A meta-analysis has shown that there is an increased risk of mortality with atypical antipsychotic use in BSPD.[44]
- Hypnotics can be considered for predominant symptoms of insomnia, however there is no evidence to support the use of benzodiazepines in the management of BPSD. Anecdotally, a short-acting benzodiazepine like lorazepam; or a Z-drug like zopiclone, is used in the short term. Potential side effects include confusion, sedation and increased risk of falls; as well as a potential risk for dependence.
- Cognitive enhancers such as acetylcholinesterase inhibitors and NMDA receptor antagonist have conflicting evidence to support their use in the management of BPSD, but they do benefit cognition.[45]

When using drugs in elderly patients with dementia, due consideration must be given to the age and disease-related changes in the pharmacokinetic and pharmacodynamic properties of the prescribed drug. Prescribing must be informed and judicious, starting at low doses, with slow and cautious titration, whilst carefully monitoring for emergence of side effects. As BPSD evolve with the progression of dementia, drug treatment for BPSD should be reassessed regularly to determine the need for the medication to be continued.

CONCLUSION

Cognitive symptoms may be the hallmark of dementia, but BPSD often overshadow the presentation and course of disease. Unlike cognitive and functional deficits with a downward trajectory of decline, these symptoms wax and wane and can last for months. As such, BPSD are difficult to prevent and manage, presenting severe problems to persons with dementia, their families and caregivers and care providers. Treatment of BPSD alleviates suffering, reduces caregiver burden and lowers societal costs in persons with dementia.

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Table 1: Types of Behavioural and Psychological Symptoms of Dementia

Disturbances of emotional experience
Depression or dysphoria Anxiety • Worrying • Shadowing (following the caregiver) Apathy or indifference Elated mood Irritability or mood lability
Delusions of abnormal thought content
Suspiciousness • Conviction that spouse is unfaithful • Belief that others have acted with malicious/discriminatory intent • Intruders coming into the home, stealing/hiding things Abandonment • Accusation that there is a conspiracy to abandon or institutionalise them Misidentification • Spouse is an imposter • The place in which one is residing is not their home Associated with depression Beliefs involving guilt, worthlessness, reference or persecution
Perceptual disturbance
• Illusions • Hallucinations
Disturbances in motor function
Motor retardation/hyperactivity Agitation • Easily upset • Repetitive, purposeless behaviour • Arguing or complaining • Pacing • Inappropriate screaming, crying out, disruptive vocalizations • Rejection of care (e.g. bathing, dressing, grooming) • Wandering away from home Aggression • Physical • Verbal Disinhibition • Socially inappropriate behaviour • Sexually inappropriate behaviour
Disturbances in circadian rhythm
• Sundowning • Hypersomnia • Insomnia • Sleep-wake cycle reversal • Fragmented sleep

LEARNING POINTS

- **Behavioural and psychological symptoms of dementia (BPSD) can have a varied presentation, with common symptoms that include mood symptoms, sleep disturbances and agitation.**
- **In the assessment of BPSD, medical causes must first be excluded.**
- **The first line of management of BPSD should always be non-pharmacological interventions where possible.**
- **Interventions must be tailored to each individual and requires the incorporation and consideration of the caregivers.**