Chapter 28

MANAGEMENT OF BEHAVIOUR IN DEMENTIA

INTRODUCTION

The dementia syndrome affects approximately 6.5% of older Australians and is characterised by cognitive impairment and a variety of non-cognitive clinical features, including psychological symptoms and challenging behaviours. The expression 'behavioural and psychological symptoms of dementia' (BPSD) was coined to provide an omnibus or umbrella term to describe these non-cognitive symptoms of dementia. These symptoms are also sometimes referred to as neuropsychiatric symptoms. BPSD include both psychological symptoms that are described by the older person and behaviours that are observed by others. This chapter provides an overview of BPSD and an approach to their assessment and management.

PREVALENCE

Most, if not all, people with dementia will develop BPSD at some point in their illness. In about 50% of cases, these symptoms will be clinically significant and either cause significant distress to the person with dementia or cause significant burden to carers, or both. In other cases, BPSD will be evident, but will not be a major focus of clinical attention or treatment. BPSD include psychological symptoms such as anxiety, depression, delusions and hallucinations, and challenging behaviours such as apathy, agitation, aggression and motor overactivity. The Cache County Study from the US state of Utah found that 97% of people with dementia had one or more BPSD at some point over a 5-year period. The 5-year prevalence of depression was 77%, of apathy was 71% and of anxiety was 62% (Steinberg et al 2008).

The persistence of BPSD has been investigated in the Maasbed Study from the Netherlands (Aalten et al 2005). In this study, 80.9% of people with dementia had one or more BPSD at baseline. The baseline prevalence of selected BPSD was as follows: apathy 40%; depression 35%; anxiety 21%; delusions 22%; hallucinations 10%; and agitation 19%. However, the prevalence of symptoms that persisted at each of four 6-monthly observation points over 2 years was much lower: apathy 12%; depression 2%; anxiety 1%; delusions 4%; hallucinations 2%; and agitation 0%. Thus, it is clear from this research that BPSD come and go. This has implications for uncontrolled research studies, as there is a significant risk in such studies that clinical improvement

might be attributed to an intervention when it actually only reflects the natural fluctuations in BPSD prevalence over time. Thus, to be meaningful, BPSD intervention studies must have a valid control condition.

BPSD also occur in people with mild cognitive impairment (MCI) (Apostolova & Cummings 2008, Muangpaisan et al 2008) and in some people with subjective memory complaints (SMC) (Sohrabi et al 2009). In the large Cognitive Function and Ageing Study (CFAS) funded by the UK Medical Research Council (MRC) (Savva et al 2009), BPSD were found to be much more prevalent in older people with dementia than in older people without dementia, but mood symptoms, apathy, irritability and feelings of persecution were found in a significant proportion of people without dementia. Thus, the term BPSD actually refers to non-cognitive symptoms that are seen across the whole range of cognitive function in older people (not just those with dementia).

SIGNIFICANCE

BPSD are one of the risk factors for residential aged care facility (RACF) placement. In a US study, Yaffe et al (2002) found that BPSD were the fourth most important risk factor for RACF placement after living alone, having a Mini-Mental State Examination (MMSE) score of 20 or less, and having one or more activities of daily living (ADLs) dependencies. Older people with BPSD were 30% more likely than those without BPSD to be admitted to an RACF. The same study found that a Zarit Burden Interview (see Ch 35) score of 20 or greater was the most important caregiver risk factor for RACF placement. People with dementia whose caregiver reported a Zarit burden score of 20 or greater were 73% more likely to be admitted to an RACF.

There is a strong association between BPSD and carer burden, distress and depression (Black & Almeida 2004). Although there are undoubtedly emotional benefits that accrue to many carers of people with dementia as a result of their valued caregiving role, most carers report at least some sense of burden. However, burden needs to be distinguished from distress and depression, although the three phenomena are not mutually exclusive.

SYMPTOM CLUSTERS

Clinicians have long observed that certain BPSD tend to cluster together and these observations have been confirmed by research techniques, including factor analysis. In a factor analytic study conducted by the European Alzheimer's Disease Consortium (Petrovic et al 2007), four factors were identified using the Neuropsychiatric Inventory (NPI): a psychosis factor (irritability, agitation, hallucinations and anxiety); a psychomotor factor (aberrant motor behaviour and delusions); a mood lability factor (disinhibition, elation and depression); and an instinctual factor (appetite disturbance, sleep disturbance and apathy). The investigators pointed out that the association between elation, depression and disinhibition might have implications for treatment.

DIFFERENTIAL DIAGNOSIS

Challenging behaviours in people with dementia can occur for a variety of reasons, including delirium, pre-existing mental health problem (including psychosis, depression and anxiety), behavioural toxicity of prescribed medication, substance abuse or

dependence, and intercurrent general medical problems (e.g. chest infection or acute coronary syndrome). Sometimes, challenging behaviours simply reflect longstanding patterns of antisocial behaviour.

Certain classes of prescribed medication are particularly prone to cause disturbed behaviour. These include sedatives, narcotic analgesics, antidepressants, antipsychotics, anticonvulsants, anti-Parkinsonian drugs, corticosteroids and chemotherapeutic agents.

AETIOLOGY

By definition, the principal aetiological factor in BPSD is thought to be the underlying dementia syndrome. However, there are substantial individual differences in the pattern and severity of BPSD that are likely to relate to other aetiological factors. Some BPSD occur more commonly in people with particular types of dementia. For example, delusions are more prevalent in dementia due to Alzheimer's disease, whereas depression is more common in dementia due to cerebrovascular disease (Lyketsos et al 2000). Behavioural disturbance occurs early in the course of the behavioural variant of frontotemporal dementia, often before cognitive impairment is obvious.

The premorbid personality of the person with dementia is likely to influence their current behaviour. In particular, there is evidence that high levels of neuroticism are a risk factor for anxiety in people with dementia, and that high levels of agreeableness protect against agitation and irritability (Archer et al 2007).

Depression may be associated with behavioural change in someone who is unable to effectively express their distress any other way. For example, there is evidence that people with dementia and disruptive vocalisation (i.e. screaming and repetitive calling out) are more likely to be depressed than people with dementia without disruptive vocalisation (Dwyer & Byrne 2000). Pain is another powerful precipitant of challenging behaviour in people with dementia, who are often unable to articulate the source of their distress. Thus, for example, pain from arthritis or from headache might lead to psychological distress that manifests as one or more BPSD.

Sometimes, the person with dementia responds with challenging behaviour because they have been abused or neglected by others. In institutional settings, rigid care schedules may evoke behavioural resistance to care. Poor hearing or eyesight can contribute to sensory deprivation, and in the context of cognitive impairment may lead to BPSD. BPSD can be manifestations of intercurrent general medical problems, including delirium (see Ch 19).

Genetic polymorphisms may also influence BPSD. These genetic variants are known to affect the activity of neurotransmitter transporter systems in the brain and are likely to play a part in why some people with dementia get severe BPSD and others get mild BPSD (Pritchard et al 2007, 2008).

SCALES TO MEASURE BPSD

Many scales have been developed to measure BPSD. Some of these are scales that measure single constructs, such as depression (e.g. the Cornell Scale for Depression in Dementia (CSDD)) (Alexopoulos et al 1988), whereas others are omnibus scales that measure a range of phenomena. Popular omnibus scales include the Neuropsychiatric Inventory (NPI) (Cummings et al 1994, Cummings 1997) and the Cohen-Mansfield Agitation Inventory (CMAI) (Cohen-Mansfield 1986).

The CSDD is a 19-item clinician-rated instrument that rates five classes of depressive symptoms on a 3-point response scale. The NPI is a set of 12 scales (see box below), covering 10 neuropsychiatric symptoms and two vegetative symptoms (appetite and sleep) rated by a clinician following an interview with a caregiver. The CMAI includes 29 challenging behaviours, which are usually rated by nursing personnel. The NPI employs response scales that rate the frequency and severity of each item, as well as the degree of caregiver distress caused by the symptom. The CMAI employs response scales that rate the frequency and disruptiveness of each symptom. The CSDD is commonly used in both clinical and research settings and is part of the routine data set collected in Australian RACFs. The NPI is commonly used in both clinical and research settings involving people with mild to moderate dementia, whereas the CMAI is commonly used in clinical and research settings involving people in RACF settings. See also Chapter 35.

NEUROPSYCHIATRIC INVENTORY (NPI) SYMPTOMS (ADAPTED FROM CUMMINGS 1997)

The 12 NPI symptoms are:

1. delusions
2. hallucinations
3. agitation/aggression
4. depression/dysphoria
5. anxiety
6. elation/euphoria
7. apathy/indifference
8. disinhibition
9. irritability/lability
10. aberrant motor behaviour
11. sleep, and
12. appetite and eating.

ELSEVIER

INITIAL ASSESSMENT OF BPSD

For the initial BPSD assessment:

- Establish the basis for the diagnosis of dementia. It is usually based mainly on clinical assessment of the person together with history from informants.
- Consider whether potentially reversible causes of dementia have been excluded, or identified and adequately treated.
- Identify and treat intercurrent depression and delirium.
- Undertake a physical examination or arrange for this to be done.
- Identify and treat intercurrent general medical problems (e.g. stroke, heart attack, infection and hyponatraemia). This will often involve arranging for the person with dementia to undergo some laboratory investigations. Commonly, these will include urinalysis, full blood examination and a biochemical profile; less commonly, these will include a brain scan (computed tomography (CT) or magnetic resonance imaging (MRI)), an electrocardiogram (ECG), a troponin level and a chest X-ray.

- Accurately characterise the nature and significance of the reported behavioural or neuropsychiatric problem. Obtain a detailed description of the problem. Do not accept brief descriptors of a problem, such as 'wandering' or 'aggression', as these words mean different things to different people. If there are multiple problems, establish which problem is most challenging or most distressing and focus on this initially. It is rarely possible to deal with multiple problems at the same time.
- Identify contextual issues (e.g. physical environment and behaviour of significantothers).
- Review the social and occupational history of the person with dementia, including premorbid personality, education, occupation and relationship history.
- Review the psychiatric history of the person with dementia.
- Identify interventions that have already been trialled and assess the adequacy of thesetrials.
- Consider the location in which the further management of the person with BPSD should take place. In most instances, it is appropriate for the management plan to be implemented in the community, wherever the person lives; in rare instances, it is appropriate to consider a hospital admission.
- Investigate in detail the antecedents and consequences of the behaviour, as a prelude to behavioural management. Antecedents include all aspects of the environment and all aspects of carer behaviour that precede a target behaviour (e.g. physical aggression is commonly preceded by attempts at showering or changing clothes). Consequences include all the things that follow a target behaviour (e.g. screaming or disruptive vocalisation is commonly followed by increased staff attention).
- Determine how to chart or monitor the target symptom over time. It is often best to employ a user-defined scale such as the Goal Attainment Scale (Gordon et al 1999)
- Consider whether treatment is necessary. If treatment is necessary, consider which treatment is likely to be most appropriate to the needs of the person with dementia and which treatment is likely to be most practicable to implement.

MANAGEMENT OF BPSD

The evidence base for the management of BPSD is rather modest. There is a dearth of methodologically rigorous randomised controlled trials (RCTs) of non-pharmacological and pharmacological interventions, apart from RCTs for atypical antipsychotic medication. The RCT evidence that is available suggests modest efficacy of all interventions. Reflecting this paucity of evidence, a wide variety of psychosocial interventions and many different medications have been proposed as treatments for BPSD.

Most clinicians adopt the philosophical position that it is better to start treatment with a non-pharmacological intervention because these interventions are less likely to do harm to the person with dementia than the pharmacological interventions. However, there are some situations in which there is little alternative but to use pharmacological interventions in an attempt to manage severe and dangerous BPSD.

Non-pharmacological management

There are two main evidence-based approaches to the non-pharmacological management of BPSD. The first involves the application of behaviour management techniques to reduce the frequency of problem behaviours. The second uses caregiver training to reduce burden, distress and depression, and to increase coping. In addition to these two principal approaches, several specific interventions have been shown to temporarily modify challenging behaviour.

Behaourm anagement

Commonly used evidence-based behaviour management techniques include stimulus control and contingency management (Logsdon et al 2007). Stimulus control involves modifying certain stimuli that are associated with an undesirable behaviour. Consider, for instance, a person with dementia who regularly becomes combative when being showered in the morning by male personnel. The stimulus control approach might suggest changing the antecedents to this behaviour. Changing from a shower to a bath, changing from the morning to the afternoon, and changing from male carers to female carers, might all modify the behaviour of the person with dementia.

Contingency management involves modifying the consequences of an undesirable behaviour in such a way as to decrease the time the person spends exhibiting the behaviour. Consider a person with dementia who screams out much of the time. Assuming that the person is not in pain or discomfort, and has no other treatable disorder, it would be reasonable to focus on shaping the symptom of screaming. Most people who scream continually do have at least short breaks when they do not scream. Although it is natural for family members or RACF staff to go to the assistance of the person with dementia when they scream, and to take a well-earned rest when the person stops screaming, this approach is likely to increase the frequency of the screaming. It does this by 'rewarding' the screaming behaviour with the attention of others. The correct, but somewhat counterintuitive, approach is to massively reward spontaneously occurring quiet periods so that the length of time that the person with dementia spends screaming decreases. This should be combined with ignoring the screaming.

The effective implementation of a behaviour management strategy is critically dependent upon relative preservation of the implicit memory (procedural memory) of the person with dementia (Parahoo et al 2006). Implicit memory is generally well preserved in cortical dementias such as those due to Alzheimer's disease. However, the application of formal behaviour modification techniques in the home or in RACF environments does pose some challenges. These include the relative lack of well-trained geropsychologists working in these settings and the counterintuitive nature of many of the interventions. In addition, in institutional settings, all personnel on all shifts must apply the intervention according to a protocol if it is to have much chance of succeeding.

Perhaps because of these challenges, many other specific types of non-pharmacological intervention have been used in people with BPSD. These include aromatherapy, massage, individualised music, simulated presence therapy, Snoezelen®, life review, reminiscence therapy, validation therapy, doll therapy and pet therapy. The use of such interventions has been critically reviewed (O'Connor et al 2009, Opie et al 1999) and the quality of the evidence found to be modest. For some such interventions, there are Cochrane Reviews. For example, Vink et al (2004) reviewed music as an intervention in dementia and found little evidence to either support or discourage the use of music therapy.

Despite this, this type of intervention is in widespread use as part of a humane program of care, particularly in RACF settings.

Caregiver counselling and training

Individualised behaviour management training for caregivers and individual or group sessions designed to improve coping are both associated with improved caregiver psychological health (Selwood et al 2007). However, supportive therapy and group behaviour management training, although popular, do not appear to work. When administered in combination with donepezil for people with Alzheimer's disease, individual and family counselling for caregivers has been demonstrated to be effective in reducing symptoms of depression in the caregivers (Mittelman et al 2008).

Pharmacological management

Because BPSD may be due to behavioural toxicity from prescribed medications, it is important to review the older person's current medication prior to considering the prescription of further medication. It is often possible to stop one or more medications without causing the person any ill effects. The best way to check on an older person's medication is to view the actual medication containers, rather than simply rely upon a list of currently prescribed medication. For a variety of reasons, the medication the person is currently taking is not necessarily the same as the computerised list provided by their general practitioner or medical specialist.

Drugs from several different classes have been trialled in people with BPSD, including cholinesterase inhibitors, the NMDA-receptor antagonist memantine, antidepressants, anticonvulsants and antipsychotics.

The cholinesterase inhibitor drugs (donepezil, galantamine and rivastigmine) that are modestly effective for the symptomatic treatment of the cognitive symptoms of dementia have been mooted also for the treatment of BPSD. Unfortunately, the cholinesterase inhibitors seem to have limited efficacy in the treatment of BPSD (Howard et al 2007). In contrast, the NMDA-receptor antagonist memantine is associated with modest improvement in behaviour in some people with dementia (Gauthier et al 2008).

Antidepressants show moderate efficacy in the treatment of major depression in people with Alzheimer's disease. While it is likely that all modern antidepressants will have some efficacy in this situation, the best evidence is for sertraline (Lyketsos et al 2003), moclobemide and citalopram.

The anticonvulsants carbamazepine and valproate have been trialled in BPSD. Valproate has been found to be ineffective (Herrmann et al 2007). The evidence for carbamazepine is more mixed, but insufficient to recommend this drug (Konovalov et al 2008). There is little evidence for the use of benzodiazepines in BPSD.

The conventional and atypical antipsychotic drugs are modestly effective (mean effect size 0.18) for the treatment of psychotic symptoms, aggression and agitation in people with dementia (Lonergan et al 2002, Rabinowitz et al 2007, Schneider et al 1990). However, they are associated with an increased risk of cerebrovascular adverse events, including stroke and transient ischaemic attacks (TIAs). They are also associated with an increased risk of death (Schneider et al 2005). It appears that this is a class effect and occurs with both atypical and conventional antipsychotics. The most susceptible individuals have preexisting risk factors for cerebrovascular disease, including, in some cases, a history of stroke or TIA. The main implication of these observations is

that clinicians should obtain informed consent (often from a substitute decision maker) before prescribing psychotropic drugs to people with dementia. They should also carefully weigh the risk–benefit ratio before prescribing antipsychotic medication. Before the patient commences antipsychotic medication, the clinician should decide upon a stopping rule (e.g. stop antipsychotic medication after 6–12 weeks to see if it is still needed). Withdrawal of antipsychotic medication from people with dementia is often quite feasible, usually leads to no adverse outcomes (Ballard et al 2008) and has been shown to reduce mortality (Ballard et al 2009).

SERVICE DELIVERY ISSUES

People with dementia vary considerably in the severity of the BPSD that they exhibit. As a consequence, a range of services is needed to meet their needs. Not all of these services are available in all locations. Older persons' mental health services (OPMHS) in some districts will be able to collaborate with other community-based service providers, particularly with the Dementia Behaviour Management Advisory Service (DBMAS), auspiced by Alzheimer's Australia.

A seven-tiered BPSD service delivery model has been developed (Brodaty et al 2003), which is illustrated in Figure 28.1. Unfortunately, at the time of writing this book,

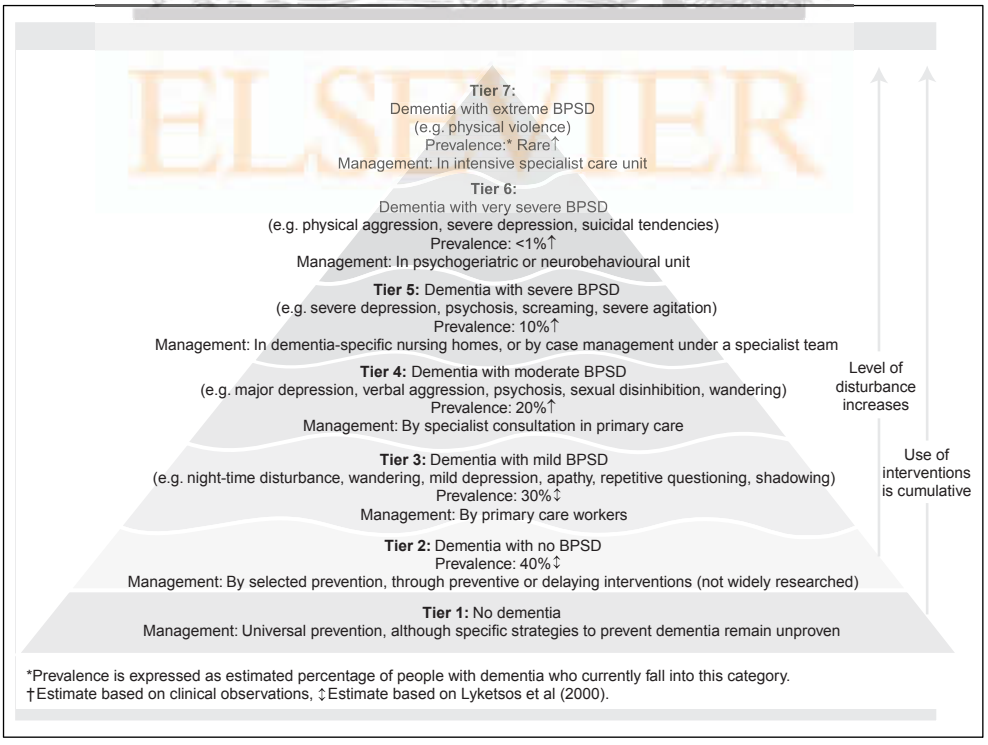

Figure 28.1 Brodaty's seven-tiered service delivery model

Source: Brodaty H, Draper BM, Low L-F 2003 Behavioural and psychological symptoms of dementia: a seven-tiered model of service delivery. Medical Journal of Australia 178(5):231–234.

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most districts in Australia do not have access to tier six and seven services. As a consequence, people with dementia complicated by severe behavioural disturbance are often managed in inappropriate settings, such as RACFs, hospital emergency departments and general psychiatric wards, by staff with inadequate training or insufficient support.

SUMMARY

BPSD are highly prevalent, and are often associated with substantial distress for the person with dementia and considerable burden for the carer. They may also lead to premature institutionalisation. Interventions include individualised behavioural management, individualised carer training and the careful use of psychotropic medications.

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