Behavioural and psychological symptoms of dementia: a seven-tiered model of service delivery

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ABSTRACT

- People with dementia usually experience behavioural and psychological symptoms of dementia (BPSD) during the course of their illness. Currently, in Australia, there is a lack of comprehensive planning for managing and preventing BPSD, and the resources required for optimal care are inadequate and unevenly distributed.
- We propose a seven-tiered model of service delivery based on severity and prevalence of BPSD, ranging from no dementia through tiers of increasingly severe behavioural disturbance to the propensity for extreme violence in a small number of individuals.
- Each tier is associated with a different model of intervention. People with dementia may move up or down between tiers depending on their condition, their care and the intervention provided.
- Lower-level interventions may prevent the need for the more intensive interventions needed when disturbance becomes more severe.

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IN 2001, Australia's population was approximately 19 million, of which an estimated 165 000 people had dementia. Projections are that by 2041 Australia's population will be 25 million, with an estimated 460 000 people with dementia.[1]

The management of dementia is complicated by behavioural and psychological symptoms of dementia (BPSD), such as psychosis, depression, agitation, aggression and disinhibition (ie, unrestrained behaviour resulting from a lessening or loss of inhibitions or a disregard of cultural constraints). BPSD is an umbrella term for a heterogeneous group of non-cognitive symptoms that are almost ubiquitous in dementia. Rates of BPSD vary according to how symptoms are ascertained, thresholds of severity, and setting. For example, rates of BPSD have been estimated at 61%–88% among people with dementia in a community setting,[2,3] 29%–90% in residents of Australian nursing homes,[4,5] and 95% among hospitalised patients in long-term acute care.[6]

The problems

BPSD create problems for the individual, the community and the healthcare system. They are associated with lowered functional abilities[7] and poorer prognosis, an increased burden on caregivers[8] and nursing-home staff,[9] higher costs of care[10] and earlier institutionalisation.[11] Hospitalised patients with BPSD are more difficult to discharge, because of the difficulty of placing them elsewhere.[12]

Currently, in Australia, services for people with BPSD are ad hoc and fragmented. It is unclear who should bear responsibility for this population. Should it be State or federal governments, geriatric or psychogeriatric services, generic mental health services or specialist mental health services for older people, primary or secondary health services? Some States have developed specialised facilities — psychogeriatric nursing homes in Victoria, psychogeriatric extended care units in Western Australia, and CADE (Confused And Disturbed Elderly) units in New South Wales — to accommodate people with dementia who cannot be cared for at home or in mainstream residential care facilities. However, these facilities are not equitably distributed and do not necessarily have special resources for people with dementia and severe behavioural complications.

The management of patients with BPSD is a particular problem in rural and remote areas, where there is a dearth of specialist services and the many partners in care tend to work independently. Modes of delivery that have been investigated in rural areas include telemedicine and specialist fly-out clinics.[13] The Alzheimer's Association has also developed some services — for example, the Alzheimer's Association (SA) has run a behaviour advisory service telephone helpline since 1999. Funding for services in rural and remote areas is unreliable or non-existent. Previous federal government initiatives have not been sustained or incorporated into routine practice. The availability of psychosocial interventions is limited. Judiciously prescribed psychotropic medications can be effective, but there are legitimate concerns about the excess or inappropriate use of medications for residents in nursing homes.[15]

A comprehensive plan for service delivery to people with dementia

We propose a seven-tiered model to assist in planning services for managing people with BPSD (see Box). This model divides people with BPSD into seven tiers in ascending order of symptom severity and decreasing levels

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of prevalence — from people with no dementia (tier 1) to the most behaviourally disturbed patients (tier 7). Treatment is cumulative from the lowest tier upwards, with those on the bottom tier receiving the least intervention and those on the top tier receiving the most. In this plan, interventions aim both to stop patients from moving to higher tiers (prevention) and to move patients to lower tiers (treatment/management). The boundaries between tiers are not distinct, and movement between levels is not necessarily stepwise. For example, an infection may precipitate a severe behavioural disturbance (moving a person from, say, tier 3 to tier 6), and treating the infection may return the patient to tier 3 status. Intervention strategies recommended for lower levels should generally be tried before employing those from higher levels.

Tier 1: No dementia

The lowest tier comprises the general population without dementia. Health promotion interventions would aim at keeping most of the population in this tier by preventing the development or delaying the onset of dementia (universal prevention). To date, no specific intervention has been demonstrated in randomised controlled trials (RCTs) to reduce the incidence of dementia. There is replicated case–controlled evidence for the protective effects of antioxidants (eg, vitamin E, vitamin C), anti-inflammatories, hormone replacement therapy, antihypertensives, folate and statins.[16] Other factors reported to be protective include cognitively stimulating social and physical activities.[16-18] Reducing BPSD would be a secondary benefit of preventing or delaying dementia. Benefits would include better quality of life, reduced healthcare costs and increased productivity as caregivers remain in the workforce.

Tier 2: Dementia with no BPSD

In the community-based Cache County Study in Utah, USA, 39% of people with dementia did not display any behavioural or psychological symptoms.[2] Currently, no interventions have been proven effective in preventing or delaying the development of BPSD. Cholinesterase inhibitors may delay the emergence of symptoms,[19] but the development of specific drugs to prevent BPSD is a long way off, as the aetiology of BPSD is not well understood. There is anecdotal evidence that caregiver training programs[20] and social and environmental interventions (such as those suggested in the Living with Memory Loss program of the Alzheimer's Association Australia[21]) may possibly prevent or delay the development of BPSD.

Tier 3: Dementia with mild BPSD

Using a predefined threshold of severity, Lyketsos and colleagues[2] reported that 29% of people with dementia have mild BPSD, such as apathy, mild depression, repetitive questioning and shadowing (ie, following other people around very closely). These behaviours may respond to distraction and reassurance and may be prevented by altering interactions and the environment.

Tier 3 management strategies comprise psychosocial interventions, usually involving family caregivers or care staff. In an RCT involving community-dwelling patients with Alzheimer's disease, training family caregivers in behavioural management techniques (involving pleasant activities or problem-solving) to alleviate depression was found to be effective in reducing BPSD, with the effects being maintained for six months.[22] Psychoeducation for family caregivers (including problem-solving and behavioural interventions) has been shown to reduce agitation and anxiety in people with dementia.[23] Behavioural management techniques have also been shown in an RCT to be as effective as haloperidol and superior to placebo in reducing agitation among people with BPSD in nursing homes.[24,25] However, these techniques are seldom used by family caregivers or nursing-home staff because of lack of knowledge, skills or resources. The evidence for other psychosocial interventions for BPSD (applicable to tiers 3 and 4) has been reviewed by Opie and colleagues.[26]

In our model, interventions for tier 3 behaviours are provided by primary healthcare workers. Medications, while not the first resort, may be prescribed by a general practitioner. Pharmacotherapy frequently involves the use of antidepressants or antipsychotics. Several placebo-controlled studies have reported the efficacy of various medications for treating BPSD — such as haloperidol and risperidone to treat aggression, agitation and psychosis in dementia, and moclobemide, citalopram and sertraline for depression.[27]

Tier 4: Dementia with moderate BPSD

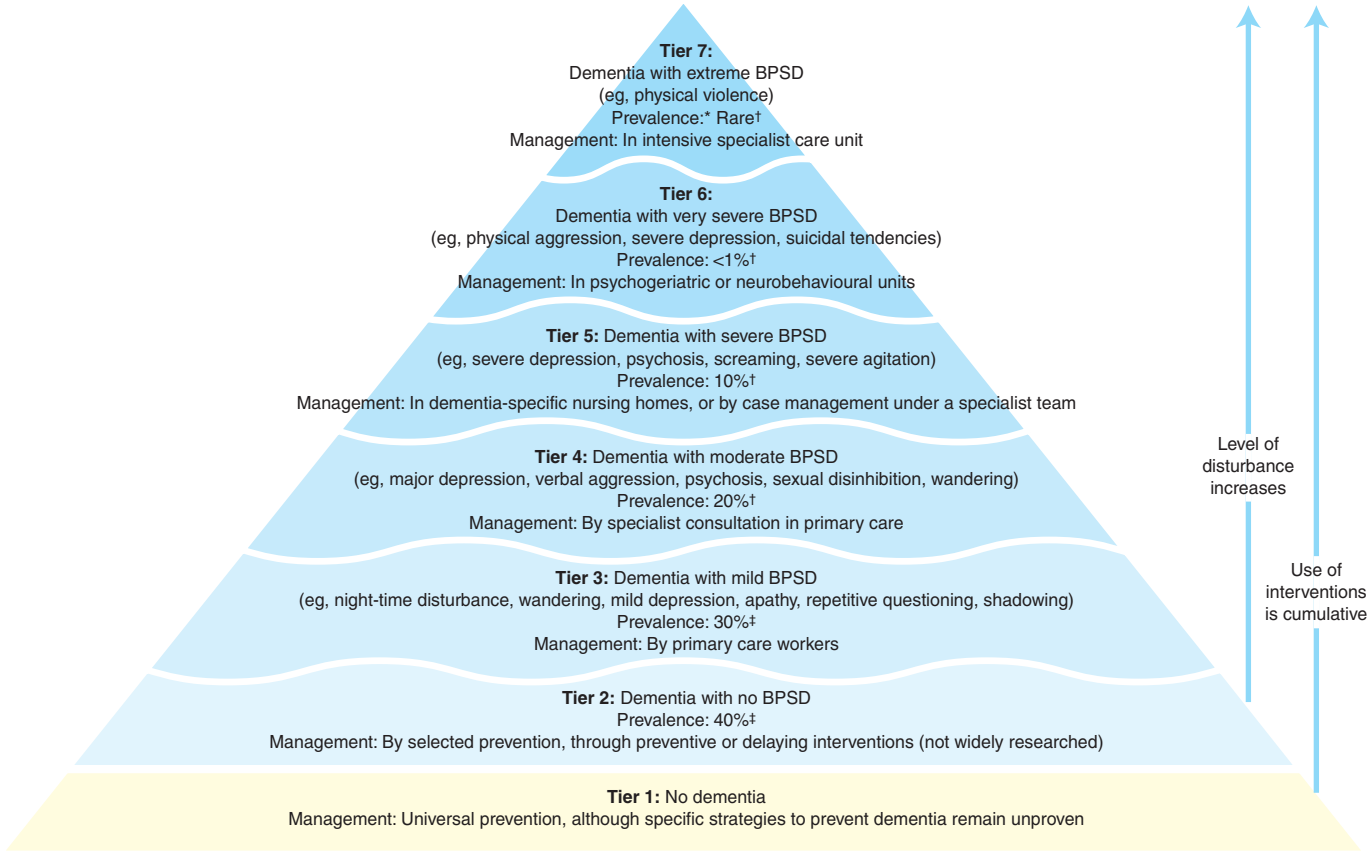
People with dementia would belong to tier 4 by virtue of the severity of their symptoms or because of the failure of tier 3 treatments. Moderately severe behavioural and psychological symptoms characteristic of people in tier 4 include major depression, verbal aggression, low-level (non-dangerous) physical aggression, psychosis, sexual disinhibition and wandering. It is difficult to determine prevalence rates of BPSD in this tier. In our study of Sydney nursing homes,[5] we found that 46.7% of residents with dementia had moderate BPSD requiring staff attention, and 38.8% had severe BPSD involving physical disturbance and/or requiring constant staff attention (unpublished data). Rates in community-dwelling people with dementia are likely to be substantially lower — we tentatively estimate that about 20% of all people with dementia may be at tier 4 level.

Tier 4 members require specifically targeted interventions. We would recommend specialist consultation (providing advice on medications), general staff and/or carer education, and tailored behavioural programs. If medical illness underlies the behavioural disturbance, referral to a geriatrician may be helpful. In hospitals, consultation–liaison approaches usually recommend prescription of psychotropic agents, further medical evaluation, advice about behavioural management and discharge planning (including transfer to a psychiatric facility if patients require tier 6 management).[28]

Tier 5: Dementia with severe BPSD

Mainstream facilities may be unable to cope with people with very severe BPSD. We estimate from our clinical experience that about 10% of people with dementia would fall into tier 5. The vast majority of people with dementia

Seven-tiered model of management of behavioural and psychological symptoms of dementia (BPSD)



*Prevalence is expressed as estimated percentage of people with dementia who currently fall into this category.
†Estimate based on clinical observations. ‡Estimate based on Lyketsos et al.[2]

and very severe disturbances such as depression, aggression and marked agitation are likely to be in residential facilities. Consultation or primary case management has failed. More intensive care can be provided within a specialist case-management model, in which tailored programs are implemented by a specialist multidisciplinary team. For example, treatment may involve a psychiatrist (or geriatrician) reviewing the cause of the disturbed behaviour, a specialist doctor prescribing medication, a nurse liaising with staff, a psychologist developing a behavioural plan, and a social worker integrating the family into the care plan. RCTs have demonstrated the effectiveness of such teams in the community and in nursing homes.[29,30]

Tier 6: Dementia with very severe BPSD

We estimate that up to 1% of dementia patients will fit this tier. They come from three groups:

- People with dementia in general hospitals who develop a superimposed delirium. They are best managed in a special medical ward conjointly by geriatricians and old-age psychiatrists, usually for some days, until their acute condition abates.
- People with acute psychiatric problems complicating their dementia. If they did not have dementia their psychiatric condition would warrant psychiatric inpatient care (eg, people who have severe depression with suicidality, whose food or fluid intake is inadequate, or who fail to respond to specialist team case management). Admission to an acute psychogeriatric unit is required, usually for a few weeks. Such hospitalisation has been shown to reduce BPSD.[31,32]
- People with severe behavioural disturbance complicating their dementia, such as dangerous physical aggression or other behaviours that residential staff or family are unable to cope with despite assistance from other services. These patients require placement in special-care facilities (eg, psychogeriatric or aged-care neurobehavioural units) for some months before returning to mainstream care. These units require secure grounds, more and better trained staff than mainstream nursing homes, and support from multidisciplinary specialist mental health services for older people. They have been shown to reduce problematic behaviours and increase socialisation.[33]

For the 165 000 Australians currently estimated to have dementia,[1] up to 1650 tier 6 beds nationally would be needed.

Tier 7: Dementia with extreme BPSD

This level of symptom severity is rare, but when it occurs the situation has usually reached a crisis. Patients in this category are generally men under 70 years of age who are very strong

and have been so violent that they have harmed other residents or staff. They often have non-Alzheimer-type dementias (eg, dementia from alcohol-related brain damage, frontotemporal dementia or vascular dementia). Management in hospital or special-care facilities has been unsuccessful, staff refuse to work with the patient, and no other facility will admit him. Such people require a high-security specialist care unit with a large ratio of male staff to patients. Only one such unit for each of the larger States may be required.

Discussion

Our model provides the basis for comprehensive planning of service delivery. We believe that it is representative of the prevalence of different severities of BPSD. Current funding is very sparse for intervention at tier 1 and tier 7 levels, even though the resource need per patient is greatest at the top and the population to be served is greatest at the bottom of the triangle (Box). Targeting funding to lower levels may reduce the demand for higher-level services — this is the principle of preventive medicine.[34] Thus, education for all staff working in residential-care settings has the potential to reduce the prevalence and severity of BPSD and the subsequent demand for more specialised (and more expensive) services.

Within Australia's healthcare system, the federal government is predominantly responsible for funding the bottom three tiers, whereas State governments are predominantly responsible for funding the top four tiers. There needs to be collaboration between State and federal governments to fund dementia and BPSD prevention education programs that will in the long term reduce the need for higher-level services, delay institutionalisation and improve quality of life for people with dementia and their caregivers.

We need to define who is responsible for whom with what level and type of disability. Avoiding the issue is costly — for example, people with dementia admitted to hospital have high rates of delirium and behavioural disturbance, have a longer length of stay, and incur higher nursing care time and costs.

Resource limitations call for a staged approach to implementing a comprehensive plan to provide services for each tier. Logic suggests that it would be best to start from tier 2 and proceed up the hierarchy, focusing especially on strategies that are evidence based.

Conclusion

We have proposed a model for the rational development of services to deal with the increasing problem of BPSD. It is time for discussions to occur in Australia at federal and State levels to formulate detailed plans for providing adequately resourced services.

Competing interests

None identified.

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