Submission by the Australian Psychological Society

Care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD)

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May 2013
Introduction

The Australian Psychological Society (APS) thanks the Senate Standing Committee on Community Affairs for the opportunity to respond to its inquiry into the care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD).

The APS is the largest professional organisation for psychologists representing over 20,000 members. The APS has a long history of working collaboratively with the Australian Government and respond to inquiries in relation to aged care, dementia care and other health and community wellbeing issues. The APS recently provided feedback to the proposed Aged Care Bill (Living Longer Living Better) 2013 and the Australian Aged Care Quality Agency Bill 2013. The APS has previously provided extensive submissions in 2010 and again in 2011 to the Productivity Commission’s Caring for Older Australians Inquiry. In addition, the APS also appeared before the Commission in its hearing in Melbourne in 2011. The APS has also been active in representational activities in relation to the Aged Care Funding Instrument (ACFI), and better access to psychological services by residents of Residential Aged Care Facilities (RACF). This submission draws on the past submissions of the APS, particularly the APS submission to the House of Representatives Standing Committee on Health and Ageing Inquiry into Early Diagnosis and Intervention for Dementia. In addition, the APS has established extensive evidence base for psychological services for various mental disorders, a full copy of which can be accessed free of charge from http://www.psychology.org.au/Assets/Files/Evidence-Based-Psychological-Interventions.pdf

Principles of care

Four principles underscored the submission of the APS to this inquiry:

1. *Ageing is a normal biological process*. The vast majority of older Australians, including those with dementia, can, with support, function independently. Policy initiatives therefore, must support the notion of “ageing in place”.

2. *Community support as a foundation for optimal care*. Integrated and coordinated community and primary care services (such as home help and community support groups) can assist people with dementia to live in their communities.

3. *Families and carers for people with dementia must also be supported*. This not only entails access to respite care, but also to information and additional services and support as their demand increases.

4. *Emphasis on evidence-based non-pharmaceutical interventions*. The cost of polypharmacy is high both at a financial level (for both individuals and through government subsidies) and a personal level (through side effects etc). More can and should be done to minimise these costs, while maintaining quality of care.
This submission will focuses predominantly on older Australians with dementia, while acknowledging that younger people also suffer from dementia. However, the principles of care for people with dementia can be applied across the age spectrum.

**A holistic view of dementia and dementia care**

Dementia is a complex and varied condition and has physical, neurological, social, behavioural and cognitive symptoms. It is also not unusual for these manifestations to occur differently in different contexts, social settings and environments. Therefore the definition of care and intervention for people with dementia must not only be viewed through the medical lens (see comments on BPSD below), but also through social, behavioural and cognitive view points and the way in which these interact and interface with each other.

One critical factor to the success of care and management of people with dementia and BPSD care is the way in which dementia and BPSD are viewed by providers in the health and community care sectors, and by others in the community. In the health and community sectors, allied health professionals such as psychologists are playing increasingly recognised and pivotal roles in the assessment, intervention and ongoing management of people living with dementia. Of equal importance is the need to raise awareness and recognition that dementia not only affects the health of individuals concerned, but also the health and psycho-social wellbeing of their families and carers.

People diagnosed with dementia do not always require residential care, although some will eventually under various circumstances. Many people with mild or even moderate forms of dementia and BPSD can live and function in their local communities with adequate and coordinated support services. With ongoing monitoring, these services can be increased or customised as required.

Therefore care and management of people with dementia and BPSD, regardless of their age, is not just about the provision of medical, pharmaceutical and allied health services, but also encompasses support services, accessible environment (transport, housing etc) and other social policies in order for these affected by dementia and their families and carers to function at their optimal capacity.

**Dementia and mental health among older Australians**

The APS draws the committee’s attention to the incidence and prevalence of behavioural and mood disturbances associated with dementia, including mental health issues. Studies in the Australian population and overseas have found the prevalence of anxiety in non-nursing home populations to be as high as 30% and the prevalence of depression around 32%. This compares with 18% in the normal population. The International Psychogeriatric Association stated that up to 90% of nursing home residents have symptoms of behavioural disturbances.

Currently, these problems are commonly treated with psychoactive medication which is expensive, frequently has undesirable side-effects and
requires regular adjustment in order to deal with issues relating to polypharmacy.

**Artificial separation between health, mental health and aged care**

Consistent with the holistic view of care and management of people with dementia and BPSD, the APS is concerned regarding the ongoing focus of health initiatives and programs in the acute health sector, and, in particular, hospitals. This is often at the expense of sub acute/rehabilitation and primary/community care sectors. Similarly, there are artificial separations between health, mental health and aged care services, driven at least in part by the funding mechanisms for each area.

The APS has consistently argued for greater alignment between aged care, mental health and health services, and greater focus and investment in community and primary care in order to maintain the health and wellbeing of individuals. There are many examples of individuals “falling through the gaps” due to the way in which services are funded, their eligibility criteria and coverage. This is a major barrier to access of quality care for people with dementia, BPSD, their carers and families.

Until greater scrutiny is applied to close the gaps between mental health, aged care and health services and greater investments in community and primary care sectors people with dementia and BPSD will continue to receive less than optimal levels of services and support. In particular, new investments should target the following:

1. Greater support for carers and families of people with dementia and BPSD;
2. Greater education for community service providers on supporting people with dementia and BPSD;
3. Better use of behavioural management techniques by carers, families and service providers in collaboration with and input from expert providers;
4. Providing services for people with dementia and BPSD in their usual environments to minimise associated distress; and
5. Greater care coordination and linkages between health and community service sectors and between acute and primary care settings.

People with dementia and BPSD often access a range of services that are funded at the Commonwealth, State/Territory levels as well as at the local government levels. This situation presents fertile grounds for blame and cost shifting. However, demand for such services often exceeds supply, particularly outside of major population centres. As a result, consumers are unnecessarily placed into RACF. In addition, the provision of care packages is often in fixed combinations, resulting in inefficiencies and waste whenever a client does not need all elements of a package.

In the area of community support, the APS has welcomed the proposed expansion of the existing community visitors’ scheme for people receiving residential care to be extended to home care under the Aged Care Bill (Living Longer Living Better) 2013. The APS is also supportive of the
proposed Australian Aged Care Quality Agency Bill 2013. However, it should be stressed that while these two Bills relate to aged care services, there are no specific Acts or Bills to the APS’ knowledge that addresses the needs of young people with dementia or BPSD.

**BPSD and its current characterisation**

As stated above, the diagnosis and management of dementia has always included a considerable emphasis on behavioural and cognitive features, and their development and modification where necessary. As the authors of the American Psychiatric Association's Diagnostic and Statistical Manual (DSM) make very clear, the type, presence and extent of behavioural disturbance is a crucial feature in establishing the diagnosis of dementia. So it is somewhat artificial for these behavioural features to be separated from the discussion and management of dementia generally. However, given their implications for cost and management it is understandable that this process has evolved.

What is disappointing from the psychologists’ viewpoint is that much of the work of the International Psychogeriatric Association in developing the principles and features of BPSD has been very focused around the medical model, without proportionate emphasis and contextualisation of the social, behavioural and psychological viewpoints. As noted above, the medical viewpoint is but one perspective, and has the tendency to view the psychological and social factors as a consequence or subset of its biological focus, rather than have the behavioural and psychological viewpoints as equal and competing perspectives. This has influenced the current views on care and management of people with dementia, namely the tendency to only think in terms of pharmacology as the natural form of treatment, rather than a suite of behavioural, environmental and psychological interventions as complementary or replacement therapies for medications.

**Early and accurate diagnosis as key to care and management**

It has been estimated that the prevalence of dementia will increase 3-4 fold from approximately 257,000 in 2010 to 981,000 by 2050 and there will be a very significant shortfall in the availability of residential aged care places (Access Economic, 2011). Early diagnosis and intervention has been demonstrated to reduce the need for residential care placement and to keep people with dementia living in the community for longer.

The ageing population must have the opportunity to obtain healthcare where they need it and when they need it, regardless of their physical location or abilities to attend health care services. Services therefore must be patient centred and flexible, allowing a seamless transition between early assessment of cognitive decline to treatment, education and advanced care planning. Equitable health care for people with dementia will keep them at home and engaged with their communities for longer, delaying the entry into residential care which has been estimated to save the government approximately $100 000 per person per annum (Weimar & Sager, 2009).

As stated above, the care and management of people with dementia needs to shift away from just a medical disease model and move towards a social and behavioural management view of the functioning and capacities. Primary health care services must be supported to engage people with early signs of
dementia as it is within their community primary care services that they seek first opinion.

One of the major and critical responses to the care and management of people with dementia is early and accurate diagnosis of the functional abilities of people.

Research evidence suggests the combination of clinical and neuropsychological assessment should be essential components of establishing correct and accurate diagnosis (Schmand, Eikelenboom & van Gool, 2011). The diagnostic contributions of clinical neuropsychologists enhances the investigative process by applying sensitive and active measures of cognitive and brain state that are powerful diagnostic tools.

In addition, these tests of brain function provide an accurate characterisation of current functioning that provides a solid foundation for prognosis and informed planning and interventions. Neuropsychological measures have been identified as the most significant prognostic indicators for Alzheimer’s disease 2 to 10 years before its diagnosis, in non-demented people (Albert et al., 2007; Artero et al. 2002; Elias et al., 2000; Tierney et al. 2005). Neuropsychological tests can also accurately predict progression within 10 years of diagnosis (Tierney et al., 2010).

Furthermore, cognitive assessment can differentiate between cognitive decline due to normal ageing or mood disorders compared with decline due to dementia related issues. Factors such as social isolation and depression remain under-recognised and under-diagnosed. Depression in the elderly is also often misdiagnosed as dementia as they present with similar symptoms (e.g., poor concentration, poor memory, low mood, and irritability). Therefore depression must always be eliminated as a differential or diagnosed as a co-morbid disorder as depression is treatable and access to skilled clinicians such as geriatricians and clinical neuropsychologists in vital to make the accurate differential diagnosis.

Case study:
Psychological interventions in aged care services are shown to be effective and cost significantly less than conventional forms of treatment. An Australian example is a multidisciplinary trial funded and published by the Commonwealth government (Bird, Llewellyn-Jones, Smithers and Korten, 2002). Led by a clinical psychologist, psychotropic medication was used in a minority of cases, but most cases employed a mix of psychosocial interventions tailored to the individual needs of the case. Over the course of the trial only one patient was hospitalised compared with more than 20% of the control group which was treated mainly with antipsychotic drugs. Drug side-effects were reported in 12 cases in the psychosocial group compared with 32 cases in the conventional treatment group. Visits by general practitioners to deal with behavioural problems reduced by half: an average of 4.5 visits in the psychosocial group and 9.4 visits in the conventional treatment group. Visits by a consultant psycho-geriatrician were also less common, an average of 1.2 visits in the psychosocial group as compared against 4.8 visits in the conventional care group. The use of antipsychotics declined in the psychosocial group and increased in the control group.
Funding should be person centred, evidence based and outcome focused

Early diagnosis means people with dementia may live in their communities longer, leading to improved quality of life by keeping them socially engaged. This also protects the quality of life of their carers, family members and local communities by enhancing the person affected by dementia’s ability to remain an active and functional member of the community.

Approximately 80% of people report that they would want to know as soon as possible if they had a diagnosis of Alzheimer’s Disease (Dale et al., 2008; Dale et al., 2006). Such information allows people living with dementia, and their surrounding care network, to begin to plan for their futures.

Neuropsychological evaluations are requested in a variety of medico-legal cases, such as whether or not a patient is legally competent to make financial decisions, and since neuropsychological test findings are objective, they are seen as valuable to the legal system in this respect (Prigatano & Morrone-Strupinsky, 2010). Early diagnosis allows greater opportunity for less restrictive decision-making devices, such as Enduring Power of Attorney, to be implemented, reducing the need for guardianship and administration orders. To ensure legal and care planning matters are collaboratively decided when the individual with dementia is still able to engage in decision making, ultimately relieves the family of the burden of these decisions later when the illness and available health services or residential care places dictate these outcomes.

Strong evidence exists that supporting and educating caregivers of people with dementia reduces the risk of placement into residential care (Mittelman et al., 2006). Informed carers are seen as primary means by which to improve the quality of life and better longer-term outcomes for people with dementia. One study in Melbourne found that three weeks after receiving educational handouts about dementia, carers described utilising a much wider variety of cognitive management strategies to manage their family member’s needs and equipped carers to provide optimal psychological support (Ryburn, Varanelli & Wells, 2011).

Improvements to quality of life can be measured at three levels:

- **At an individual level**, it can mean the perception one feels secure and certain of their health and service needs in line with their dementia progress. This requires accurate and up to date information, so that individuals and their carers feel in control and have some degree of certainty about their future.

- **At a local community level**, it means that people with dementia can still have active social engagement with their familiar surrounds. This is both an effective and efficient intervention approach. It is much more economical to provide care at a local level where people with dementia have existing support networks rather than in an expensive medical or aged care setting.
At a societal level, it means that people with dementia are seen and accepted as part of the broader community. This is not dissimilar to the way in which people with mental illness and other disabilities have been destigmatised and accepted into the community in the past twenty or so years. People with dementia can make positive contributions to the society, once they have local supportive services in place that are sensitive to their needs.

One way of illustrating the above is in local community organisations such as senior citizen’s clubs and support services for people with mental illnesses. Such organisations are often run by dedicated volunteers, and often without professional support and backup. One way to strengthen these organisations’ effectiveness is to provide education and training on dementia and BPSD, its prognosis and services available by qualified health professionals. This empowers both local residents and organisations to reach out and discuss issues without having to “see a professional”. Providers and service organisations remain in the background, while the face-to-face work is done by the local community organisations with support from the former on regular basis.

It is acknowledged that at some stage, a transition is required so that healthcare and social service providers will play a more prominent role. By having local organisations doing much of the groundwork as described above, it will create an atmosphere of trust and acceptance between local organisations and service provider organisations, ensuring much smoother transition process and therefore decrease any associated stress. Once again, people with dementia will enjoy improved quality of life and they will be in an active partnership with service providers, as they have already been “cared for” by their local communities via the providers.

Reducing restrictive practices

The APS draws the committee’s attention to the APS publication: Evidence-based guidelines to reduce the need for restrictive practices in the disability sector. These guidelines were developed in consultation with experts and aims to increase the use of positive behaviour support programs. These guidelines can be used in dementia care settings and can be accessed from http://www.psychology.org.au/Assets/Files/Restrictive-Practices-Guidelines-for-Psychologists.pdf

Conclusion

The provision of safe, affordable and accessible services for people with dementia and BPSD goes beyond the health sector, and includes community services, as well as justice and welfare sectors. Funding for services in these sectors is largely patchy, uncoordinated and unresponsive to the wellbeing and function of people with dementia and BPSD.

Time and accurate diagnosis underpins the care and management of people with dementia and BPSD. Further policy initiatives should focus on evidence-based interventions, particularly in the community sector, that support people with dementia and BPSD, their carers and families, in order to enhance quality of life and maximise functional potential in their local
communities. This requires a greater recognition on the contribution of psychosocial experts such as psychologists and the importance of capacity building among carers and support networks in the community.
References


