Cognitive Dementia and Memory Service (CDAMS)

Literature Review

Alissa Westphal
Academic Unit for Psychiatry of Old Age
The University of Melbourne

Prepared for the Victorian Department of Health as part of the review of CDAMS practice guidelines, 2013.
# Table of Contents

Dementia Diagnosis and Treatment of Aboriginal and/or Torres Strait Islander Peoples ............. 3

Dementia Diagnosis and Treatment in Adults with an Intellectual Disability. ................................. 8

Younger Onset Dementia: Diagnosis and Treatment: ................................................................. 14

Assessment of Dementia: ............................................................................................................. 25

Pre-clinical and Prodromal Alzheimer's Disease and Mid Cognitive Impairment: Assessment and
Follow-Up. ................................................................................................................................. 31

Treatment Using Anti-Dementia Medications............................................................................. 37

Uptake of Recommendations and Follow-Up Provided by Specialist Dementia Assessment
Clinics. ........................................................................................................................................ 41

Outcome Measures ..................................................................................................................... 47

Driving and Dementia ................................................................................................................ 52

Advance Care and Future Care Planning .................................................................................... 60

Telehealth ...................................................................................................................................... 67
Dementia Diagnosis and Treatment of Aboriginal and/or Torres Strait Islanders Peoples

Background

Indigenous Australians or Aboriginal and Torres Strait Islanders (ATSI) have poorer health and shorter expected life spans than any other group within Australia. Most studies reporting on prevalence of dementia in this population have been conducted in the remote Kimberley community in Western Australia. Estimates suggest that the prevalence of dementia amongst ATSI peoples is at least 3 times the national average (Broe et al, 2013, Smith et al 2008) with a lower age of onset and more males being affected than females (Smith et al, 2010). Risk factors associated with developing dementia include smoking, lack of formal education, head injuries, past stroke, and epilepsy are far more prevalent in ATSI communities (Smith et al, 2010; Smith et al, 2008). Other factors associated with dementia in this community include poor mobility, falls and incontinence (Smith et al, 2010).

Close to 38,000 ATSI peoples reside in Victoria comprising 0.75% of the state’s population and of these, 7727 are aged 45 or older (ABS, 2011). Recent survey of ATSI peoples residing in Victorian identified higher rates of physical and mental illnesses than non-indigenous Victorians (Department of Health, 2011). It is not known whether the prevalence of dementia amongst ATSI Victorians differs significantly from their northern counterparts.

Despite the prevalence, ATSI peoples face enormous challenges in addressing the needs of those with dementia, as the concept of dementia has traditionally not been part of their culture. ‘Whitefella sickness’ (Woenne-Green 1995, p.v), ‘childlike’, ‘madness’, (Arkles et al, 2010), ‘sick spirit’ (Arabena, 2007), and ‘sickness’ (Pollitt, 1997) are all terms in the literature that have been used to describe the disease. Understanding of dementia is poor (Garvey et al, 2010). Dementia has been attributed to ‘old age, head injury, lack of family visits and brain changes’ (Smith et al, 2011, p5). ‘Looking out for Dementia’ is a DVD resource developed to raise awareness of dementia in remote ATSI communities (Linderman et al, 2012). The success of this tool in raising awareness was dependent upon collaboration within the community and various health and community service sectors.

Seeking help for those with dementia is challenging and complicated, particularly if services do not provide care that meet the holistic needs of ATSI peoples. There can be a reluctance to engage with mainstream health services and assessments may be best carried out in an environment the person is comfortable in (Politt, 1996). ‘Genuine engagement’, ‘communication and coordination’, Community-based and culturally appropriate care’, ‘valued and supported Aboriginal workforce’ and ‘education and training’ have all been identified as central to the delivery of culturally sensitive and safe care for ATSI peoples (Smith et al, 2011).

Diagnosis

Best practices indicate that diagnosing dementia should involve interviews with the person and informants, direct assessment of the person’s functioning and cognition, assessment for, and treatment of any medical and psychiatric illnesses and a scan of the person’s brain. Issues with the standard range of cognitive assessment tools has been documented. Older ATSI peoples tend to have had poorer access to schooling and may have lower levels of literacy in English and ATSI languages. Their vision tends to be poorer than non-indigenous Australians. Cognitive tests reliant on writing or reading are likely to provide inaccurate results. In response, the Kimberley Indigenous Cognitive Assessment (KICA) was developed as a culturally appropriate assessment tool for assessing dementia in ATSI peoples in remote and rural communities. A screening version of the KICA has also been developed and validated (LoGiudice et al, 2010). Both tools are freely available and may be downloaded from the internet.

KICA: [http://www.wacha.org.au/kica.html](http://www.wacha.org.au/kica.html) The KICA is administered to the patient and the family. The Patient assessment involves collecting social, medical, smoking and alcohol histories, and assessing cognition (KICA-Cog) and mood (KICA-Depression). Informant history is collected from the family on the person’s medical, smoking and alcohol histories, the person’s cognitive functioning (KICA-Carer), behaviours (KICA-Behaviour) and participation and functioning in activities of daily living (KICA-ADL).


KICA Regional Urban: Cognitive Assessment: [http://www.wacha.org.au/kica.html](http://www.wacha.org.au/kica.html) The KICA Regional Urban Cognitive Assessment was adapted from LoGiudice et al, 2005 and developed for use with urban and regional ATSI peoples including Victorians aged 45+.

Standard cognitive assessment tools such as the Rowland Universal Dementia Assessment Scale (RUDAS) which is a ‘culturally fair’ tool may be used for ATSI peoples who are literate or where English is their second language (Rowland et al, 2006; Storey et al, 2004). Sansoni et al (2007) suggest that the question on judgement in the RUDAS may not be appropriate for ATSI peoples.

Informant interviews are an essential component when assessing for dementia. Pollitt (1997) suggests consideration be given to the following:

- Exercise sensitivity when asking about the person’s behaviours as these questions may be perceived as rude and disrespectful.
- Sometimes the person may refuse to answer questions if they are concerned that the information will be used against them.
- Services may be declined if any staff are perceived as being rude.
- Talking to informants is often more successful in obtaining information than ‘administering a structured informant interview’ (p159)
- Establishing rapport is essential in assisting the informant to open up and feel comfortable.

Interpreters should always be arranged in the person’s preferred language (Smith et al, 2011)
Treatment

Research focussing on treatment of dementia in ATSI communities is in its early days. Reduction of dementia related risk factors and improving protective factors have been suggested as areas for treatment (Arkles et al, 2010; Henderson & Broe, 2010; Smith et al, 2008; Smith et al, 2010).

Supporting the carer and assisting them with care planning is vital. Support should include: provision of information on the disease, management of behavioural and psychological symptoms, engaging the person in activities, linking them with services and providing strategies to aid communication, care delivery, and manage stress and continence issues (Dementia Collaborative Research Centre, 2012). Advanced care planning should be discussed (Dementia Collaborative Research Centre, 2012).
Dementia Diagnosis and Treatment of Aboriginal and/or Torres Strait Islander Peoples

References:


Woenne-Green, S (1995). *They might have to drag me like a Bullock*. Aged and Community Care: Canberra.
Diagnosis and Treatment of Dementia in Adults with an Intellectual Disability

Background

Adults with intellectual disabilities are living longer and experiencing many age related diseases, including dementia. Down syndrome is currently the most common cause of intellectual disability. It accounts for approximately 60 babies born in Victoria each year (Down Syndrome Victoria, 2008). It has a high prevalence of younger onset Alzheimer's disease and this prevalence increases with age. Almost 10% of people with Down Syndrome aged in their 40s are diagnosed with the disease, with this proportion increasing to 36.1% and 54.5% of those aged in the 50s and 60s respectively (Prasher et al, 1993). The increase in life expectancy of those with Down syndrome to more than 60 years of age means that more Victorians with Down Syndrome will suffer from Alzheimer's Disease as they age, and this number is expected to increase by 100% in the coming 35 years (Larsen et al, 2008).

The predominant perspective in explaining the high prevalence of dementia in Down syndrome relates to the presence of 3 copies of chromosome 21 (trisomy 21), present in 95% of those with this condition (Lemere et al, 1996, Rumble et al, 1989). A gene in this chromosome is responsible for the production of the amyloid precursor protein. The extra set of the chromosome 21 is thought to result in increased production of this protein, resulting in excessive development of amyloid in the brain. Amyloid is implicated in the development of plaques and tangles in the brain associated with Alzheimer's disease. Almost all people with Down syndrome have these plaques and tangles by the age of 40, but not all develop Alzheimer's disease. More recently, abnormalities in a gene on chromosome 19, responsible for apolipoprotien E (APOA), have been implicated in increasing the risk and decreasing the age of Alzheimer's disease onset and shortening the life expectancy of those with Down syndrome (Prasher et al, 2008).

Estimates of prevalence of dementia in adults with other types of intellectual disabilities vary greatly. Epidemiological studies suggest that dementia is as prevalent, if not more prevalent, than the general population. The annual incidence of dementia is up to 5 times higher than the general older population (Strydom et al, 2013). These figures are likely to vastly underestimate the problem, as studies often do not include people with milder intellectual disabilities who are not in receipt of disability services.

Diagnosis

An international working group was convened in 2001 to establish principles for the care and treatment of people with intellectual disabilities and dementia. One of their seven principles is that there should be “appropriate diagnostic, assessment and intervention services and resources …available to meet the individual needs and support the health ageing of people with ID affected by dementia” (Wilkinson & Janicki, 2002, p280).
Early Identification

It is well documented that diagnosing dementia in those with intellectual disabilities is challenging, particularly in the earlier stages. Adults with intellectual disabilities have lifelong lower baseline of cognitive functioning than the general population and this can vary from mild to severe. This diversity in functioning makes applying diagnostic criteria difficult. Early dementia related changes are often ‘an exaggeration of already existing behaviours and deficits that exist’ (Kerr, 2009, p9). The person may be perceived as 'stubborn' or 'challenging' when in fact they are exhibiting signs reflective of cognitive deterioration. Families and carers are often not aware that dementia may develop, especially at an earlier age. Furthermore, they often experience difficulties in services that are skilled in assessing for dementia in adults with intellectual disabilities (Carling-Jenkins et al, 2012).

Despite the difficulties associated with early identification of symptoms, it is widely accepted that doctors are able to recognise dementia consistently when it has sufficiently progressed. The Centre of Developmental Disability Health Victoria recommends that all adults with intellectual disabilities have an annual health assessment so that any health issues can be promptly identified and appropriately addressed. Establishing a good baseline assessment of cognition and functioning at age 30 has been recommended for those with Down syndrome (Oliver, 1998) with regular reviews to screen for changes.

Assessment

Debate continues over which diagnostic criteria tool (DSM-IV, ICD-10, DC-LC) can be best used in diagnosing dementia in those with intellectual disabilities (Strydom et al, 2007; Strydom et al, 2010). Consensus exists that assessment for dementia in adults with intellectual disabilities must be conducted with care and be comprehensive. Dr Torr (2009) has provided an overview of the assessment process which includes:

1. A history including their: baseline level of functioning; changes in functioning, communication, behaviour and emotions; and onset and progression of these changes. "Decline in everyday function (whether prospective change from baseline or reported retrospectively by carers) appears to be a better screening method from dementia than memory decline, particularly for participants with moderate/severe ID". (Jamieson-Craig et al, 2010, p34). Family and/or carers who have known the person longitudinally should be engaged in this informant process. Where available, more than one informant should be engaged (Burt & Aylward, 2000; Janicki et al, 1996).

2. Medical Assessment and Mental State Exam: Physical and psychiatric comorbidities are prevalent in this population. Sometimes these comorbidities or the effects of medications used to treat them, may be mistaken for or may contribute to, the person's cognitive and functional decline. "All potential causes of cognitive impairment and functional decline need to be excluded, corrected or taken into account” (p6).

3. Neuroimaging: CT or MRI brain scan should be completed where not contraindicated.

4. Cognitive Assessment: Assessment tools used to screen for dementia in the general population are generally not suitable or validated for use with those with intellectual disabilities. Repeat assessment is advocated where there is no existing baseline
cognitive measure (Janicki et al, 1996). There are a number of assessment tools developed for use with this population. For further information refer to: Aylward et al, 1997; Strydom & Hassiotis, 2003; Hoekman & Maasant, 2002; Deb, 2003; and the British Psychological Society & Royal College of Psychiatrists, 2009 (http://www.rcpsych.ac.uk/files/pdfversion/cr155.pdf). The CAMDEX-DS (Ball et al, 2006) is one readily available and easy to use tool, that does not require administration by a clinical psychologist.

Down syndrome & Dementia

Some evidence suggests that Alzheimer's disease presents atypically in people with Down syndrome (Ball et al, 2010; Ball et al 2008; Holland et al, 1998). Frontal lobe changes in personality and executive functioning have been identified as preceding declines in memory in a pre-clinical stage of dementia in those with Down Syndrome. Disinhibition was the most common early change in behaviour. They conclude that the lateral orbitofrontal cortex which regulates socially appropriate behaviour is the first area to change in pre-clinical Alzheimer's.

Early Alzheimer's changes have been identified in the area of explicit memory, with difficulties in encoding and retrieving information being affected (Krinsky-McHale et al, 2002). Depression is a frequent comorbidity in those with DS (Burt et al, 1992; Prasher & Hall, 1996) whilst psychotic symptoms are less likely to be present (Prasher, 1997). Some evidence to suggest that those with Down syndrome who have higher levels of baseline cognitive functioning, have a lower rate of developing dementia (Temple et al, 2001).

Other Intellectual Disabilities & dementia

Research in diagnosis of dementia in intellectual disabilities that are not Down syndrome is limited. In an epidemiological study in the UK, Strydom et al (2007) found the initial changes observed by carers were declines in functioning, particularly in self care, and changes in behaviour and emotional expression. The most common cause of dementia was Alzheimer’s disease, followed by Lewy body dementia, then fronto-temporal dementia, with vascular dementia the least common. Depressive symptoms have been found to be a common co-morbid mental health issue.

Treatment for dementia in those with intellectual disabilities

Cognitive enhancing drugs such as memantine, donezepil, rivistigmine and galantamine, are used in the treatment of Alzheimer’s disease in the general population. It is expected that these would work equally well on those with intellectual disability and Alzheimer's disease (Prasher & Fernando, 2009). However, few studies have been conducted in with this cohort. Cochrane reviews completed on galantamine, rivastigmine and memantine were unable to locate any randomised controlled trials in this population (Mohan et al, 2009a-c). In their review of donezepil they located one randomised controlled trial where modest benefit was found in a small cohort with Down syndrome.
Prasher and Fernando (2009) reviewed a range of different pharmacological treatments for dementia including: non-steroidal anti-inflammatory drugs, antioxidants, oestrogen, Ginkgo biloba and antipsychotics. Readers are referred to their paper for further information.

The process of diagnosis can be a relief to some family members and carers as it confirms their suspicions that something has in fact changed. Diagnosis though, can bring a whole new set of worries about the future. Information tailored to the carer's needs and situation has been identified as being helpful in supporting carers (McLaughlin & Jones, 2010) including information about communication strategies, behaviour management strategies and scheduling of activities (Furniss et al, 2011). Accessing aged based services to assist in supporting the adults with intellectual disabilities and dementia is often problematic for families. Assistance and advocacy is needed to ensure that services are not denied to these individuals (Carling-Jenkins et al, 2012).
Diagnosis and Treatment of Dementia in Adults with an Intellectual Disability

References:


Younger Onset Dementia: Assessment and Treatment

Introduction

Younger or early-onset dementias are defined as those where the age of onset is under 65 years, or for Aboriginal and Torres Strait Islanders, under 50 years. Access Economics (2011) projections for 2013 estimate that 5.7% of those diagnosed with dementia in Australia will be aged under 65 years old. This accounts for 16,609 Australians, a quarter of which reside in Victoria (Deloitte Access Economics, 2011). Estimates for 2011 provided by the Australia Institute of Health and Welfare (2012) are considerably higher, at around 23,900 Australians. Younger onset dementias are more prevalent in males (Jefferies & Agrawal, 2009).

Pre-Diagnosis Period

The pre-diagnosis period for those with younger onset dementia is lengthy and typically very challenging for the person with dementia and their family/carers (Brown et al, 2012; van Vliet et al, 2011). The time between symptom onset and diagnosis is longer for those with younger onset dementia compared with late onset dementia, an average of 2.8 years versus 4.4 years (van Vliet et al, 2013). Younger onset frontotemporal dementia has the longest pre-diagnostic period whilst vascular dementia has the shortest (van Vliet et al, 2013).

Behavioural symptoms are often first to present, in particular, apathy and social withdrawal (van Vliet et al, 2010; van Vliet et al, 2011; van Vliet et al, 2012). Initial symptoms are typically not identified, and when they are, these symptoms are not attributed to a dementia syndrome. Furthermore dementia is not suspected because of the person’s age, health and physical fitness (Harris & Keady, 2004; Werner et al, 2009). Frequently help is not sought until the behavioural, cognitive, personality and functional changes impact significantly on the person’s family (Luscombe et al, 1998; van Vliet et al, 2011). During this time, workplace issues may arise as a result of reduced productivity, conflict and inability to manage. Loss of employment may occur causing considerable financial burden. The person may hide or deny the problems and their relationships with family members often become increasingly strained and conflicted (van Vliet et al, 2011).

In most cases, help is sought from the family’s General Practitioner (GP; Luscombe et al, 1998). However, compared to people with late onset dementia, those with younger onset have more difficulty obtaining an accurate diagnosis (Bakker et al, 2010; Luscombe et al, 1998). Again, dementia is often not considered as a possible diagnosis, misdiagnoses are common and referral for specialist assessment is generally delayed (Armari et al, 2013; Mendez, 2006; van Vliet et al, 2011). Whilst early diagnosis and intervention is advocated it is often not the reality (Brown et al, 2012).

Diagnosis of Younger Onset Dementia

Diagnostic Process

The diagnostic processes for early and later onset dementias are similar. However, there are some differences. In those presenting with symptoms of a younger onset dementia,
consideration must also be given to a broader range of potential causes of cognitive and functional decline. Rosser et al (2010) and Jeffries and Agrawal (2009) provide excellent overviews of the diagnostic process and this is briefly summarised below:

1. Differential Diagnoses: Consideration must be given to other illnesses which may cause dementia-like symptoms. Examples of differential diagnoses include: delirium, Korsakoff’s syndrome, anoxic brain injury, herpes simplex encephalitis, MCI, depression, dissociative disorder, traumatic brain injury, normal pressure hydrocephalus, stroke, encephalitis, vasculitis, MS, drugs, endocrine disorders, B12 deficiency, systemic lupus erythematosus, sarcoidosis (Jeffries & Agrawal, 2009), sleep apnoea, and transient epileptic amnesia (Rossor et al, 2010).

2. History: Collection of information from the person presenting with cognitive problems as well as an informant is vital. Information collected should include:
   a. Functional, behavioural and cognitive baseline and changes
   b. Pattern of onset of symptoms
   c. Current medical and psychiatric illnesses
   d. Medical history
   e. Psychiatric history
   f. Family history
   g. Drug and alcohol history
   h. Assessment of risk issues

3. Cognitive assessment: The spectrum of cognitive domains should be assessed including frontal lobe functioning. Neuropsychological assessment may be used to determine the location and extent of cognitive deficits and assist with identifying the type of dementia. It may also be used to measure the speed of cognitive decline over 2 or more assessments. The results of neuropsychological assessment may be used to develop strategies which build on the person’s cognitive strengths.

4. Behavioural and psychiatric assessment

5. Physical assessment

6. Neurological assessment

7. Other tests (taken from Jeffries & Agrawal, 2009; Rosser et al, 2010):
   a. Blood pathology tests. Standard dementia screen blood pathology tests. Additional tests may include syphilis serology, HIV test, autoantibodies, antineuronal antibodies and CD4 count.
   b. Imaging. Magnetic Resonance Imaging (MRI), single-photon emission computed tomography (SPECT) and positron emission tomography (PET).
   c. Other. Lumbar puncture test may be indicated where the dementia is atypical, rapidly progressing and there are symptoms of an encephalopathy or focal neurological signs. A skin biopsy may assist with the diagnosis of CADASIL. An EEG may be used to detect partial seizures which may be causing amnestic syndromes.

**Younger Onset Dementia Types**

People with a younger onset dementia are more likely to have a rare or uncommon dementia type and the clinical manifestation of the disease may be different compared to late onset...
dementia (Licht et al, 2007; McMurtray et al, 2006; Mendez, 2006). The distribution of dementia types differs between those with younger onset and those with late onset, as shown in Figures 1 and 2.

**Figure 1.** Breakdown of younger onset dementia types. Data from Sampson et al, 2004, figure taken from p381, Jefferies & Agrawal (2009).
Brief overviews of the main types of younger onset dementias are provided below:

**Alzheimer’s Disease:** Alzheimer’s Disease accounts for approximately one third of those with younger onset dementia and is more common in females than males. Differences between early and late onset Alzheimer’s disease have been reported. Younger onset Alzheimer’s disease tend to be more aggressive and present atypically, for example, with non amnestic features (Koedam et al, 2010; Mendez et al, 2012) and more impaired executive functioning (Kaiser et al, 2012). Familial Alzheimer’s disease is more common in those with younger onset dementia, but despite this accounts for a relatively small proportion of people with younger onset Alzheimer’s disease (Joshi et al, 2012). The age of onset of familial Alzheimer’s disease is earlier, 41.8±5.2 years, than non-familial younger onset Alzheimer’s disease, 55.9±4.8 years (Joshi et al, 2012). Mutations on three amyloid precursor genes on chromosome 21 have been associated with genetic variants of the disease (Lautenschlager & Martins, 2005). Cognitively and functionally, the symptoms of familial Alzheimer’s disease are similar to those seen in late onset Alzheimer’s disease. Myoclonus is often present (Ryan & Rossor, 2010).

**Vascular Dementia:** Vascular dementia is the second most common cause of younger onset dementias. The types of cognitive impairments vary according to the location and extent of brain damage. Cerebral autosomal dominant arteriopathy with subcortical infarcts and leukoencephalopathy (CADASIL) is an uncommon type of younger onset vascular dementia. CADASIL is caused by a genetic mutation in the Notch 3 gene on chromosome 19 (Joutel et al, 1996) which results in deterioration in the smooth muscle of blood vessels (Joutel et al, 2000). The majority of people with CADASIL experience migraines with auras (Abid-Sammii et al, 2010). Other symptoms include epileptic seizures, vascular cognitive impairment, depression, subcortical transient ischemic attacks and lacunar strokes (Desmond et al, 1999; Joutel et al, 1996). Age of onset of symptoms ranges from twenties to seventies with a mean age of 33.6 years (Adib-Sammii et al, 2010). Hypertension and smoking contribute to the progression of symptoms (Adib-Sammii et al, 2010; Singhal et al, 2004). Estimates suggest approximately 60% of those with CADASIL experience cognitive impairments with 66% progressing in severity to dementia (Charlton et al, 2006; Lautenschlager & Martins, 2005). Adib-Sammii et al (2010) found a lower rate of dementia with a higher prevalence in males. Age of onset of dementia is 54.6±9.7 years (Abid-Sammii et al, 2010) and the average age of death is 60 (Desmond et al, 1999).

**Frontotemporal Dementia:** Approximately 13% of younger onset dementias are frontotemporal dementias. The mean age of onset varies between 52.8±8.7 years (Ratnaavalli et al, 2002) and 57.9±9.0 years (Rosso et al, 2003). Between 20-40% of frontotemporal dementias are familial (Rosso et al, 2010). Frontotemporal dementias are characterised by degeneration in the frontal and/or temporal lobes of the brain.

There are two main types of frontotemporal dementia:

1. Behavioural form: Behavioural variant frontotemporal dementia which are characterised by changes in behaviour and personality.
2. Language forms: Primary progressive aphasia or semantic dementia which are characterised by changes in speech and language.

An estimated 10% of people with motor neuron disease develop frontotemporal dementia.

**Alcohol-Related Dementia:** Alcohol-related dementia accounts for approximately 12% of people with younger onset dementia. Heavy and prolonged alcohol intake damages the frontal lobes and limbic system resulting in executive dysfunction and memory difficulties. Some people experience improvements in functioning following abstinence from alcohol.

**Lewy Body Dementia:** Lewy body dementia affects a relatively small proportion of people with younger onset dementia. Historically, it has been a diagnostic challenge and consequently often misdiagnosed. This is largely because it is closely associated with Alzheimer’s disease and Parkinson’s disease with many overlapping symptoms (McKeith et al, 2005). Lewy body dementia is characterised by the presence of Lewy bodies in the brain. The primary features of this dementia include fluctuating cognition and alertness, Parkinsonian type symptoms, autonomic nervous system dysfunction, disturbed sleep patterns and visual hallucinations, which are usually vivid and detailed (Jeffries & Agrawal, 2009). Severe sensitivity to antipsychotics and frequent falls are also often seen, and abnormalities in the basal ganglia are evident on PET or SPECT scans (McKeith et al, 2005).

There are many other causes of younger onset dementia including Huntington’s disease, Creutzfeldt-Jakob disease and HIV related dementia.

### Treatment of Younger Onset Dementia

People with younger onset dementias typically have different needs to their older counterparts. They are more likely to be employed, have a dependent family, have financial commitments and be otherwise physically well (Jeffries & Agrawal, 2009; Luscombe et al, 1999; van Vliet et al, 2011). The diagnosis of dementia significantly impacts all of these areas of functioning and has a tremendous impact on the person’s spouse/partner and their children. As a result, interventions should always be person-centred and individually tailored to address the needs of the person with dementia, their spouse/partner/carer and their children/family. Historically, services available to support the needs of people with dementia and their carers have been aimed at the older population. Increasing attention is now being given to establishing effective services and interventions that meet the needs of those with younger onset dementia and their families (Brown et al, 2012).

**Person with younger onset dementia:** The diagnosis and information on prognosis should be provided to the person and their family (where consented) in easy to understand terms, supplemented with written information and delivered in a staged manner (Armani et al, 2013; Brown et al, 2012). Poor communication of diagnosis has been cited as an issue in an Australian study (Brown et al, 2012). Management of those with younger onset dementia should include pharmacological and non-pharmacological interventions. These may include:

- Prescription of medications or supplements where indicated (Jeffries & Agrawal, 2009). These may be used to slow the progression of dementia or to manage other
physical and psychiatric co-morbidities. Cholinesterase inhibitors, memantine and Souvenaid may be used for those diagnosed with Alzheimer’s disease. Medications may also be used to treat behavioural and psychological symptoms associated with dementia.

- Cardiovascular health should be optimised. In particular, attention should be paid to increasing physical activity and improving nutritional intake (Jefferies & Agrawal, 2009).
- Strategies to assist with functioning may be provided and cognitive training/exercises recommended (Jefferies & Agrawal, 2009).
- Counselling and support, including peer support, should be offered to provide the person with opportunities to understand and adjust to the diagnosis and prognosis (Brown et al, 2012).
- Opportunities should be provided for engagement in meaningful activities in an appropriate setting (Brown et al, 2012; Chemali et al, 2010).
- Opportunities to continue employment should be explored if this is what the person wants. Assessment of the person’s work capacities may be conducted and where indicated supported employment opportunities may be considered (Robertson et al, 2013).
- Environmental changes may be recommended and made to maximise familiarity of the surrounds, minimise environmental stress and support their functioning, e.g. signage and increased lighting (Jefferies & Agrawal, 2009).
- Aids may be used to support daily functioning. For example, dossette boxes, reminder alarm, key finders and orientation clocks.
- Driving ability should be assessed and monitored (Armari et al, 2013).
- Assistance with daily activities, for example with personal care tasks, in a manner that utilises their strengths (Brown et al, 2012).

**Spouses/Partners:** The impact of younger onset dementia on spouses/partners is considerable. They face an uncertain future, which brings with it a multitude of worries and fears (Bakker et al, 2010). Stress is higher for spouses/partners who are working and many have to reduce or cease work as caring needs increase (Luscombe et al, 1998). The marital role is gradually superseded by the role of carer and loss and grief are common responses. Spouses/partners are left to make decisions without the person. Lack of information and support, social isolation and financial concerns contribute to their burden and stress. Psychiatric illnesses are common (Kaiser & Panegyres, 2007; Luscombe et al, 1998; Mendez, 2006). Interventions may include:

- Assistance with community and domestic activities of daily living, such as shopping and cleaning, which can assist in alleviating some of the carer related burden (Bakker et al, 2010; Kaiser & Panegyres, 2007).
- Education, counselling, training and support may assist in providing spouses/partners with: emotional support as they adjust to the diagnosis, the ensuing changes and their emotional responses; and developing coping strategies (Armari et al, 2013; Brown et al, 2012; Kaiser & Panegyres, 2007).
- Planned activity groups and/or respite care may provide the spouse/partner with much needed breaks from their caring roles (Jefferies & Agrawal, 2009; Kaiser & Panegyres, 2007).
• Assistance to identify and refer to appropriate services (Brown et al, 2012).
• Advice and practical support to assist the spouse/partner to access financial support (Amari et al, 2013; Brown et al, 2012).
• Advice on availability and accessing dementia counselling and information for their children (Jefferies & Agrawal, 2009).
• Legal issues should also be addressed, for example, advance care planning and banking arrangements (Brown et al, 2012).

Information and appropriate services and support need to be accessible and available to the spouse/partner as their needs change (Amari et al, 2013; Bakker et al, 2010).

Children of the person with dementia: Children are more likely to experience stigma as a result of their parent’s diagnosis. They are also likely to have difficulties coping with and managing the changes in their parent’s behaviour, personality, cognition and functioning (Luscombe et al, 1998). Little evidence exists concerning interventions aimed at supporting and assisting children of a parent diagnosed with younger onset dementia (Rosenthal Gelman & Greer, 2011). Denny at al (2012) provide a list of interventions targeting children. These interventions include:

• Education and information on:
  o Dementia in language they can understand.
  o How to deal with the changes in their parent’s behaviours and functioning.
• Support and counselling to assist children with:
  o Dealing with the changes they see in their parent and their parent’s relationship.
  o Their worries.
• Practical strategies to:
  o Communicate with their friends and family about the disease
  o Provide physical assistance to their parent.

In the case of familial dementias, genetic counselling should be provided and genetic testing recommended (Joshi et al, 2012).
Younger Onset Dementia: Assessment and Treatment

References


Cognitive Dementia and Memory Service (CDAMS)

Literature Review


van Vliet, D., de Vugt, ME., Bakker, C. et al. (2013). Time to diagnosis in young-onset dementia as compared with late-onset dementia. Psychological Medicine, 43(2), 423-432.

Assessment of Dementia

Assessment is vital to correctly diagnosing and treating people with dementia. Dementia results in impairments in cognition, functioning and behaviour. With this in mind, assessment of people with mild cognitive impairment and dementia should include tools that assess these domains. This brief review will focus on cognitive screening tools and assessments of functional abilities and behavioural and psychological symptoms. Neuropsychological assessment tools are beyond the scope of this review. For a detailed review of assessment tools refer to the Dementia Outcome Measurement Suite at http://www.dementia-assessment.com.au/measures.html. A range of tools have already been presented under review of outcome measures. For information concerning other domains of assessment please refer to that section. For a review of computer based cognitive assessment tools that are being used for the assessment of cognition in mild cognitive impairment refer to Snyder et al (2011).

Cognitive Screening Tools

The spectrum of dementia related disorders affect a number of different domains. Cognitive tests rarely cover the full domain of functions that may be impaired and so more than one test is often required. The domains that should be assessed as part of a comprehensive assessment include:

- ‘Learning and memory’
- ‘Attention and concentration’
- ‘Speech and language abilities’
- ‘Executive functions’
- ‘General intellectual competence’
- ‘Visuo-spatial and visuo-constructional skills’
- ‘Sensory perceptual abilities’
- ‘Psychomotor speed’.

At a minimum the Dementia Outcome Measurement Suite recommend that the testing completed ‘should include attention, expressive and receptive language, memory, constructional ability and abstract reasoning’.

From: Sansoni et al, 2007, p109

The Dementia Outcome Measurement Suite recommends the following cognitive screening tools be used:

- Modified Mini Mental Exam 3MS (McDowell, 2006; Teng and Chui, 1987); May be used in place of the MMSE as it is freely available at no cost unlike the MMSE.
Cognitive Dementia and Memory Service (CDAMS)

Literature Review

- Alzheimer’s Disease Assessment Scale – Cognition ADAS-Cog (Rosen, Mohs, and Davis, 1984): This test requires additional training to administer. Rated as a valid tool for people from culturally and linguistically diverse communities (CALD).
- Rowland Universal Dementia Assessment Scale RUDAS (Storey, Rowland, Basic, Conforti, and Dickson, 2004): Rated as a valid tool for CALD communities and should be used with an interpreter where needed. Better able to detect dementia in an Australian sample compared with MMSE and GPCOG and was less influenced by CALD status (Basic et al, 2009). The single item testing judgement may not be suitable for use with ATSI peoples.
- Montreal Cognitive Assessment MOCA (http://www.mocatest.org/): designed to identify mild cognitive impairment. It is available in 37 languages.
- Addenbrookes’ Cognitive Examination ACE-R (Mioshi et al, 2006) – Sensitive to early stages of dementia and is able to differentiate between Alzheimer’s disease, FTD, progressive supranuclear palsy and other Parkinsonian syndromes.
- EXIT-25 (Stokhold et al, 2005) – Assesses executive functions.
- Frontal Assessment Battery FAB (Dubois et al, 2000) – Assesses executive functions. Can distinguish FTD from mild AD.

The Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) is an informant based screen for cognitive impairment that may also be used (Jorm, 2004). The IQCODE is available in a number of different languages in short and long versions. See:


For more detailed information about assessment of dementia in people from CALD backgrounds refer to:

- A review of available translated cognitive assessment tools for older people from CALD backgrounds completed by Vrantsidis, LoGiudice, O’Connor, Dow, Runschi & Traynor can be found at: http://www.dementia.unsw.edu.au/index.php?option=com_dcrc&view=dcrc&layout=project&Itemid=112&research_topic=15&researcher=0&research_type=0&year=0&population=0&centre=0&keywords=&searchtype=EXACT&pid=16&search=true
Functional Assessment Tools

Functional assessment tools used in a dementia assessment clinic context should cover personal and instrumental activities of daily living (ADLs). A dementia diagnosis requires a person's functioning to be significantly impacted. The tools recommended by the Dementia Outcome Measurement Suite include:

- Alzheimer’s Disease Cooperative Study – Activities of Daily Living Inventory (Galasko et al, 1997). This assessment covers a broad range of personal, domestic and community ADLs, as well as leisure engagement. It is administered to an informant who spends at least 2 days a week with the person.
- Disability Assessment for Dementia DAD (Gelinas et al, 1999) – The DAD assesses personal, domestic and community ADLs, as well as leisure engagement.
- Cleveland Scale for Activities of Daily Living (Patterson & Mack, 2008) – The CSADL assesses personal, domestic and community ADLs, as well as communication and social behaviour.

All of these tools take approximately 15 minutes to complete with an informant.

Assessments of Behavioural and Psychological Symptoms of Dementia

Up to 90% of those with dementia will experience BPSDs during the course of the disease trajectory (Lyketsos et al, 2002; Steinberg et al, 2004; Zuidema et al, 2007). The presence of these symptoms has a significant impact on the person experiencing them, their family members and carers. A wide variety of BPSD assessment tools exist, some of which are broad, whilst others are more symptom specific. Tools that assess a variety of symptoms are likely of more value within a dementia assessment clinic setting. The tools recommended by the Dementia Outcome Measurement Suite include:

- The Neuropsychiatric Inventory NPI (Cummings, 1994). The NPI assesses the presence and severity of the spectrum of BPSDs including those prominent in frontotemporal dementias. It also assesses the impact these symptoms have on the carer.
- Behavioural Pathology in Alzheimer's Disease BEHAVE-AD (Reisberg, Borenstein, et al. 1987). The BEHAVE-AD was designed for use with persons who have Alzheimer’s disease, but has been used with people who have other dementias. It is not suitable for assessing symptoms that would be common in people with frontotemporal dementia.

Assessment of depressive symptoms which can impair cognition is important within dementia assessment clinics. Depression is very common in those with dementia, affecting around one third of sufferers (Lyketsos et al, 2002). Two tools recommended for assessment of depressive symptoms by the Dementia Outcome Measurement Suite are:

1. The Cornell Scale for Depression in Dementia CSDD (Alexopoulos et al, 1988): The CSDD involves an interview with the person being assessed, as well as an interview with an informant.
2. Geriatric Depression Scale GDS (Sheikh & Yesavage, 1986): The GDS is a commonly used tool to assess for depression in the elderly. It has versions of different lengths 30, 15, 10 and 4 questions. The GDS is available in several different languages and has been used in a number of different countries see:

http://www.mednwh.unimelb.edu.au/nari_research/pdf_docs/6_GDS.PDF

The CSDD takes approximately 20 minutes to complete whilst the GDS 5-10 minutes.
Assessment of Dementia

References:


Pre-Clinical & Prodromal Alzheimer's Disease and Mild Cognitive Impairment

Assessment & Follow-Up

Considerable change has occurred over the past 5 years in our understanding of mild cognitive impairment (MCI) and its relationship with dementia. Research has focussed on:

1. Establishing consensus in defining types of MCI.
2. Understanding the rates of transition of MCI to dementia.
3. Identifying biomarkers in those who do transition from MCI to dementia.
4. Identifying treatments that may prevent or slow progression from MCI to dementia.

This review will provide an overview of diagnostic criteria and assessment of pre-clinical and prodromal (MCI) Alzheimer's disease.

Pre-Clinical Alzheimer's Disease

The National Institute on Aging (NIA) and the Alzheimer’s Association (AA) have developed criteria for defining preclinical Alzheimer's disease (Sperling et al, 2011). It is anticipated that diagnostic criteria for this stage will be included in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) which is due to be published in May 2013. Changes associated with Alzheimer’s disease are believed to start many years before the clinical presentation of the disease. Pre-clinical Alzheimer’s is the period of time when pathophysiological changes are occurring, although there are no obvious clinical symptoms. People with pre-clinical Alzheimer’s disease have biomarker evidence of these pathophysiological changes. The NIA and AA provide research criteria for 3 stages of pre-clinical Alzheimer's disease. These stages taken from Sperling et al (2011) are as follows:

1. Stage 1: People with ‘asymptomatic cerebral amyloidosis’. Biomarkers present are high PET amyloid tracer retention and/or low CSF Aβ42.
2. Stage 2: People with ‘amyloid positivity and evidence of dysfunction and/or early neurodegeneration. Biomarkers present are amyloid positivity and: neuronal dysfunction in an Alzheimer’s disease pattern on FDG-PET/fMRI and/or high CSF tau/phospho-tau and or/cortical thinning and/or hippocampal atrophy on volumetric MRI.
3. Stage 3: People with amyloid positivity and evidence of neurodegeneration and subtle cognitive decline. Biomarkers are as in stage 2 plus, there is evidence of subtle changes from baseline functioning and the person may demonstrate slight decline in functioning on sensitive cognitive assessments. It is thought that this is the stage before MCI (see Figure 1). It is unclear what the clinical predictors of transition to MCI will be, e.g. decline in testing or subjective reports of decline.
Pre-clinical Alzheimer's disease is an emerging area of research. Defining the criteria for stages of pre-clinical Alzheimer's disease provides a base for further research into treatments targeting different stages of the pre-clinical disease process that may halt the progression of amyloid changes and neurodegeneration such that transition to MCI may be slowed or halted.

The speed of progression from pre-clinical Alzheimer's disease to mild cognitive impairment is not yet known. Research suggests that those who progress through all 3 stages of pre-clinical Alzheimer's disease, are at an increased risk of converting to MCI or Alzheimer's disease.
(Knopman et al, 2012). No recommendation was available for frequency of follow up for persons with this diagnosis. Debate exists concerning diagnosing this early in the disease process as there is no readily available treatment (Knopman & Caselli, 2012).

Mild Cognitive Impairment and Prodromal Alzheimer’s Disease

Mild cognitive impairment (MCI) is the state between normal cognition and dementia. Some people with MCI remain this way for the rest of their lives, whilst some go on to develop Alzheimer’s or other dementias. A meta-analysis of 41 cohort studies (Mitchell & Shiri-Freshki, 2009) found an annual conversion rate of between 5-10% with cumulatively 39.1% MCI developing dementia and Alzheimer’s being the most prevalent dementia type developed (33.6%).

The National Institute on Aging and the Alzheimer’s Association workgroups have developed criteria for defining MCI. These criteria, taken from Albert et al (p271-272, 2011), are:

1. ‘Concern regarding a change in cognition’. This may be from the person, an informant or a skilled clinician.
2. ‘Impairment in one or more cognitive domains’. Episodic memory is most commonly affected, but other domains that may be affected are: language, executive functions, attention and visuospatial skills. Scores on cognitive tests ‘are typically 1-1.5 standard deviations below the mean for their age and education matched peers on culturally appropriate normative data’. Episodic memory impairment is most commonly seen in those who progress to Alzheimer’s disease. Cognitive tests for MCI or prodromal Alzheimer’s disease should test the cognitive domains of memory, executive functioning, attention, language and visuo-spatial skills.
3. ‘Preservation of independence in functional abilities’. Mild difficulties with instrumental activities of daily living (IADLs) may be present. They may require more time to complete tasks and make more errors. Marshall et al (2011) have found that executive dysfunction and impairment in IADLs predicts progression to Alzheimer’s disease.
4. ‘Not demented’
5. Not the result of other systemic or brain diseases.

MCI & Prodromal Alzheimer’s Disease Biomarkers

Research continues in identifying biomarkers that would enable identification of Prodromal Alzheimer’s Disease and MCI. These biomarkers tend to be most associated with prodromal Alzheimer’s disease.

1. Mutations in some genes associated with Alzheimer’s disease (e.g. APP, PS1, PS2, APOE alleles) are suggestive of prodromal Alzheimer’s disease.
2. Biomarkers reflecting Aβ – CFS Aβ42, PET amyloid imaging
3. Biomarkers of neuronal injury – CFS tau/phospho-tau, MRI (hippocampal volume or medial temporal atrophy), FDG-PET imaging, SPECT perfusion imaging.
4. Other biomarkers associated with biochemical changes – inflammatory markers (cytokines), oxidative stress (isoprostanes) and markers of synaptic damage and neurodegeneration.

At present the most reliable diagnosis of prodromal Alzheimer’s disease can be made when the person meets the criteria for MCI, has a positive Aβ biomarker and a positive biomarker for neuronal injury (Albert et al, 2011). They have an intermediate likelihood of having prodromal Alzheimer’s disease if they only have one of the biomarkers where the other has not or could not be tested. Therefore, it is unlikely to be prodromal Alzheimer’s disease if the biomarkers are negative.

Treatment for MCI & Prodromal Alzheimer’s Disease

There are no medications indicated for the treatment of MCI or Prodromal Alzheimer’s Disease. The following non-pharmacological interventions show some promise in treating some of the cognitive symptoms associated with MCI:

- Physical activity. For reviews see: Lautenschlager et al, 2010; Teixeira et al, 2012;

Follow up of MCI & Prodromal Alzheimer’s Disease

Refer to the review on Follow up under the section ‘Uptake of recommendations and follow up provided by memory clinics’.
Pre-Clinical and Prodromal Alzheimer's Disease and Mild Cognitive Impairment – Assessment & Follow-Up

References:


Treatment using Anti-Dementia Medication

There are two main types of medications that are prescribed to slow the progression of damage caused by Alzheimer's disease. Cholinesterase inhibitors, namely Donepezil, Rivastigmine and Galantamine are prescribed to slow the breakdown of acetylcholine. Whilst Memantine acts on the glutamergic system by blocking N-methyl-D-aspartate glutamate receptors.

Cochrane reviews have found that the cholinesterase inhibitors are effective for 'mild to moderate Alzheimer's disease' (p2, Birks, 2012) and has a 'clinically detectable effect on cognitive function in ... moderate to severe dementia' (p.2, McShane et al, 2009). More detailed review of the efficacy of these medications is beyond the scope of this review.

All four medications require an authority script and can only be prescribed under PBS to a person who has a diagnosis of dementia, made either by the GP and confirmed by a specialist, or made by a specialist (see http://www.nps.org.au/publications/health-professional/nps-radar/2011/november-2011/brief-item-alzheimers-change-listing). Improvement in their cognition must be demonstrated on cognitive testing completed in the first 6 months of commencing the medication. The Cholinesterase inhibitors can be prescribed under PBS to people with mild to moderate Alzheimer's disease, where the MMSE is 10 or higher. Whilst Memantine may be prescribed to people with moderately severe dementia, where the MMSE is between 10 and 14. At 3 to 6 months, there must be a 2 or more point increase in MMSE score, or if MMSE is 25 points of higher than a decrease in ADAS-Cog score of 4 or less points.

Switching Anti-Dementia Medications

Anti-dementia medications may be changed because the person experiences side effects or the person fails to benefit from the drug. There have been no double blinded studies on switching anti-dementia drugs. The following guidelines have been recommended for addressing both of these issues in a review by Massoud et al (2010):

1. Side effects/Medication intolerance: The person should be removed from the medication and a second medication should not be trialled until the side effects have resolved. The second medication should be commenced at the usual starting dose and then titrated 'by periods no less than four weeks' (p6., Massoud et al, 2010).
2. Lack of effect in the first 12 months: The medications may be changed over night to the usual starting dose of the second medication and then titrated fortnightly.
3. Loss of effect beyond 12 months: Changing is not usually recommended. Addition of Memantine for those taking cholinesterase inhibitors may be beneficial.

In 2011, $60 million was spent by the Australian Government to subsidise these medications. A recent study of PBS prescribing of anti-dementia drugs in Australia found 80% of prescriptions continued beyond 6 months, even though clinical trials have found that only 28% of people show cognitive improvement in the first 6 months (Centre for Health Economics, Monash University et al, 2012). Of further concern was their finding that 30% of people prescribed cholinesterase inhibitors were also taking other drugs that had sedative and anti-cholinergic
properties. These drugs are known to reduce the efficacy of cholinesterase inhibitors. Current contention surrounds how the Australian Pharmaceutical Benefits Advisory Committee will respond to this.

**Review and Long Term Use of Anti-Dementia Medications**

People commenced on anti-dementia drugs in Australia must be reviewed within 6 months of starting treatment. Best practice guidelines (Fillit et al, 2006) recommend follow up reviews at 2 months post diagnosis and then every 6 months to measure the effectiveness of any interventions at the beginning of the dementia care trajectory. But this is not specific to persons on anti-dementia drugs. Ongoing review of the medications tends to be completed by GPs.

Little is known about the long term efficacy of cholinesterase inhibitors and Memantine. There are no randomised controlled trials investigating efficacy of cholinesterase or Memantine beyond 12 and 7 months respectively. An open label study of donepezil has reported benefits at the 24 month mark (Doody et al, 2001). Another observational study of 201 patients treated with cholinesterase inhibitors and Memantine over 6 years found that they both delayed time till death and the cholinesterase inhibitors delayed functional decline (Zhu et al, 2013).

**Other Pharmacotherapy Treatments**

The most recent consensus statement by the British Association for Pharmacology provide a good review of evidence of other treatments including those for Lewy bodies, vascular, frontotemporal and other dementias (O’Brien & Burns, 2011). They report the following:

- There is evidence that cholinesterase inhibitors can improve both cognitive and neuropsychiatric symptoms of dementia with Lewy bodies and that related to Parkinson’s disease. Memantine may also produce cognitive and global improvements in dementia with Lewy bodies.
- Cholinesterase inhibitors and memantine should not be prescribed in people with vascular dementia but those with mixed vascular and Alzheimer’s disease may benefit.
- Cholinesterase inhibitors should not be used in people with frontotemporal dementia. There is some evidence to suggest that SSRIs may assist with behavioural symptoms of frontotemporal dementia but they do not improve cognition.
- Cholinesterase inhibitors are not helpful in treating progressive supranuclear palsy.
- Cholinesterase inhibitors and Vitamin E are not effective in reducing the risk developing Alzheimer’s disease in people with MCI.
- Gingko biloba is not effective in improving cognition in people with dementia or preventing dementia.
- Statins are not effective in preventing dementia or improving cognition in those with Alzheimer’s disease.
- Hormone replacement therapy is harmful and should not be prescribed for treatment or prevention of dementia or Alzheimer’s disease.
Medical Nutrition

Medical nutrition is another focus of treatment, particularly for Alzheimer's disease. Souvenaid, a drink containing nutrients needed in people with Alzheimer's disease including those that assist in supporting synaptic formation, has just been released in Australia for use with people with mild Alzheimer's disease. In a 24 week randomised control double blinded study, improvements were found in memory performance and changed EEG outcome suggesting changes in brain functioning activity (Scheltens et al, 2012).
Cognitive Dementia and Memory Service (CDAMS)

**Literature Review**

**Treatment using Anti-Dementia Medication**

**References:**


Uptake of Recommendations and Follow-Up Provided by Specialist Dementia Assessment Clinics

Being given a diagnosis is a defining moment for many people, their family and caregivers. It is also an event often associated with provision of considerable information typically inclusive of the diagnosis, prognosis, treatment recommendations, including referrals to other community agencies, and follow up plans. Uptake of information, treatment recommendations and referrals has been highlighted as an issue in people newly diagnosed with dementia, their family and caregivers.

Uptake of Recommendations

The most relevant and only comprehensive study evaluating uptake of recommendations in a memory clinic setting comes from The Netherlands. Wolfs et al (2010) investigated the uptake of recommendations made to persons newly diagnosed with dementia (n=252) and their family carers (n=252). Counselling (for the person or caregiver) was recommended most frequently (92.9%), followed by pharmacological treatment (40.9%), day activity programs (35.7%), caregiver support groups (23.8%) and home support services (20.6%). Three months after the recommendations were made, the majority of people had used the counselling service (88%), 75.5% followed through with the recommended medications, 60% with activities, 73.3% with carer support groups and 15.4% with home support services. One or more treatment recommendations have been declined by 64.3% of persons with dementia/carer dyads. Whilst admissions were only recommended 14.3% of the time, they were declined more than half of the time (58.3%). The most common reasons for not following through with medication recommendations related to side effects (62.5%) or concern about medical comorbidity contraindications (37.5%). Reasons for declining some treatments included the perception that it was not needed just yet or due to refusal by the person with dementia. Caregivers of persons with dementia who had lower MMSE scores were less likely to utilise counselling and to have the person admitted to hospital. Some dyads remained unaware of the recommendations that were made.

Service Utilisation and Predictors of Use

In Australia, one in three caregivers of persons with dementia are not utilising any services (Brodaty et al, 2005). The main reasons for caregivers not using services summarised from Brodaty et al (2005) and supported from other studies are:

1. Perceived lack of need. Caregivers who had low levels of burden and informal support in providing care tended to report not needing services (Brody et al, 1989; Caserta et al, 1987; Opie, 1991; Milne et al, 1993).

2. Reluctance or resistance to using services. Caregivers who were reluctant to use services tended to have a high level of care related burden, high care demands and lack of informal support. Reasons for resistance to service uptake included: denial of the need, perceived invasion of privacy or interference, perceived threat to their role as a...
Cognitive Dementia and Memory Service (CDAMS)

Literature Review


3. Services being inconvenient or unavailable. Caregivers who fell into this category tended to have high levels of care related burden, but were willing to use services. Reasons for services being inconvenience included: service inaccessibility caused by cost, eligibility criteria or hours, and concerns about quality of care (Caserta et al, 1987; Collins et al, 1994; Gibson et al, 1996; Hamilton et al, 1996; Morgan et al, 2002).


Predictors of accepting/using services include: cohabitation of the carer and person with dementia (Kaisey et al, 2012), less severe dementia and greater comorbidity or physical impairment (Brodaty et al, 2005; Kaisey et al, 2012). People from culturally and linguistically diverse communities are least likely to be using services (Brodaty et al, 2005). Attempts continue to construct caregiver typologies that may assist with selecting intervention approaches that best suit where the carer is at (Corcoran, 2011). Caregivers who adopt problem-focussed coping are more likely to formulate and implement interventions (Tschanz et al, 2013)

Strategies for Maximising Up-take of Recommendations

The following list strategies contained in the literature for maximising uptake of memory clinic and/or service recommendations:

- Provide people with dementia and their caregivers with an overview of treatment options, information about services and recommendations available for the person. A decision aide or algorithm may be a useful visual way of providing an overview of the services and how and why (Brodaty et al, 2005; Wolfs et al, 2010).
- Case management can assist with ensuring that the services and treatment options are provided when the need arises (Laakkonen et al, 2008; Wolfs et al, 2010).
- Diagnosis can be an emotionally overwhelming event and as a result, recommendations for treatment may not even be comprehended or retained. When this is the case, the person with dementia and their caregiver are at greater risk of being unsupported. Provision of written summaries of assessment visits and feedback to families, can assist greatly with uptake of information and recommendations. (Wolfs et al, 2010). It is important that this information is individualised to suit the needs of the person and family members (Karnielli-Miller et al, 2012).
- Where possible, health professionals engaged with the person with dementia and/or their caregiver should refer them to services, rather than rely on them self referring (Brodaty et al, 2005).

Follow-Up Post Diagnosis

Follow up of people diagnosed with mild cognitive impairment or dementia is part of good clinical care, however, there has been little research on this area of late. A recent multi-site randomised controlled study of the effectiveness of follow up by GPs compared to memory
clinics for newly diagnosed people with dementia, found no significant differences in the quality of life, mood or care burden (Meuuwsen et al, 2012). In a study of 1214 family members of people diagnosed with Alzheimer’s disease by Finish memory clinics, half reported dissatisfaction with the follow up (Laakkonen et al, 2008). Inadequate time to ask questions, lack of information and being unable to ask questions because of the shock of diagnosis, were all cited. This finding is not unusual (Connell et al, 2004). Flexibility for follow up discussion and information seeking immediately following diagnosis has been suggested (Bunn et al, 2012; Hean et al, 2011; Laakkonen et al, 2008). This may be in the form of phone contact of a follow up visit.

Further follow up visits to a memory clinic post diagnosis are also necessary in many cases, in order to measure the effects of medications, in particular ‘anti-dementia’ drugs, and for re-assessment where a diagnosis has not been determined or is mild cognitive impairment. Best practice guidelines (Fillit et al, 2006) recommend follow up reviews at 2 months post diagnosis and then every 6 months to measure the effectiveness of any interventions at the beginning of the dementia care trajectory. Provision of reviews differs markedly in the literature. Lindesay et al (2002) found that only 33% of the memory clinics in the British Isles offered reviews. Another study of a rural and remote Canadian memory clinic reported that reviews are offered routinely at 6 weeks, 12 weeks, 6 months, 12 months and then every year (Morgan et al, 2009). Videoconferencing is used to facilitate some of the reviews and overcome the barrier of distance to travelling to the clinic. Lee et al (2010) reported that in another Canadian memory clinic, follow ups are provided to persons newly diagnosed with MCI at 6-9 months and 3 months if medications have been started or changed. Annual reviews are offered otherwise, with more frequent reviews available if the dementia is rapidly progressing or if initiated by the GP.

In Australia, persons started on ‘anti-dementia’ drugs under the Pharmaceutical Benefits Scheme must demonstrate an improvement in their MMSE score (2+ points) or ADAS-Cog (4+ points) within the first 6 months of commencement to continue receiving PBS subsidised scripts (Brodaty & Cumming, 2010). These drugs are often commenced in the context of a memory clinic, with reviews for re-administration of the cognitive tests occurring within the 6 month window.
Uptake of Recommendations and Follow Up Provided by Specialist Dementia Assessment Clinics

References:


Cognitive Dementia and Memory Service (CDAMS)

Literature Review


Outcome Measures

There have been relatively few publications in the last 5-6 years about outcomes related to the provision of memory clinic services. These have focussed on outcomes associated with the following areas:

1. Demographics of persons accessing the clinics including diagnoses given and treatment provided/recommended (Banerjee et al, 2007; Lee et al, 2010).
3. Experiences and satisfaction of those diagnosed and their family members/carers with their clinic contact and care (Hean et al, 2011; Willis et al, 2009)
4. Quality of life of those diagnosed (Banerjee et al, 2007; Mate et al, 2012)
7. Changes in behavioural and psychological symptoms (Banerjee et al, 2007)
8. Quality of the memory clinic service including: staffing, number of referrals including those of culturally and linguistically diverse persons, speed of response, number of assessments, number of diagnoses and early diagnoses given and number of follow ups provided (Banerjee et al, 2007; Hean et al, 2011).
9. Comparison of clinic based memory clinic models with other models (Gibson et al, 2007)

Outcome measures are typically selected depending on what is of interest from an evaluative perspective for those completing the evaluation. The Australian Dementia Outcome Measurement Suite Project (Sansoni et al, 2007) reviewed available outcome measurement tools in dementia care and developed a list of recommended tools and associated website. Further evaluation of outcome measures is beyond the scope of this review.

Selection of outcome measures should incorporate quantitative and qualitative measures. The following lists areas that may be considered for measuring outcomes in the provision of specialist dementia diagnostic services for those with early to mid stage dementia.

1. Global severity of impairment – Global Deterioration Scale (GDS); Clinical Dementia Rating Scale(CDR); Dementia Severity Rating Scale (DSRS).
2. Cognition – Modified Mini Mental Exam (3MS); Alzheimer’s Disease Assessment Scale – Cognition (ADAS-Cog); Rowland Universal Dementia Assessment Scale (RUDAS); Kimberly Indigenous Cognitive Assessment (KlKA-Cog); Montreal Cognitive Assessment (MOCA). The ADAS-Cog and RUDAS are rated as being tools valid for use with people from culturally and linguistically diverse (CALD) communities. In an Australian study comparing the MMSE, RUDAS and GPCOG, they found that the RUDAS was better about to detect dementia and was less influenced by CALD status (Basic et al, 2009). The KIKA-Cog is valid for use with rural and remote Indigenous Australians.
3. Functional abilities – Alzheimer’s Disease Co-operative Study - Activities of Daily Living Inventory (ADCS-ADL); Disability Assessment for Dementia (DAD); Cleveland Scale for Activities of Daily Living (CSALD).
4. Depression – Cornell Scale for Depression in Dementia (CSDD); Geriatric Depression Scale.

5. Behavioural and psychological symptoms of dementia – Neuropsychiatric Inventory (NPI); Behavioural Pathology in Alzheimer’s Disease (BEHAVE-AD).

6. Quality of Life – DEMQOL; Quality of Life in Alzheimer’s Disease (QOL-AD). The QOL-AD is specific for persons with Alzheimer’s disease.

7. Frontotemporal assessment (Executive functioning) – Frontal Assessment Battery (FAB); EXIT 25; ACER-Cognitive Functions.

8. Frontotemporal assessment (neuropsychiatric symptoms) – Frontal Behavioural Inventory (FBI); Frontotemporal Behaviour Scale (FBS).

9. Patient/person assessed satisfaction with services: Measuring the satisfaction and collecting feedback from the person receiving the service including their family members/carers is vital to evaluating service outcome. Providing person and family centred care is key principle to the health independence programs model of care (Victorian Government Department of Human Services, 2008). Sansoni et al (2007) cite 7 key constructs developed by Hawthorne (2006) that a measure of patient satisfaction should include (p.309):
   a. ‘Health services access, environment and care coordination
   b. Provision of health information which helps to set patient expectations
   c. The relationship between the patient and health care staff, specifically empathy with the patient
   d. Participation in making choices regarding health treatment, including the associated fears and loss
   e. Satisfaction with the treatment provided...
   f. The effectiveness of treatment...
   g. A general satisfaction with the experience of health care’. The Dementia Outcome Measurement Suite suggest having one overall rating of patient satisfaction, for example (from p.314):

   How satisfied are you with your health care?
   Very satisfied
   Satisfied
   Not sure
   Dissatisfied
   Very dissatisfied

The Short Assessment of Patient Satisfaction (SAPS) is not a dementia specific tool but may be used to collect information on many aspects related to the person’s experience.

10. Impact on the carer and how they are managing: Outcomes that may be collected include:
    a. Carer’s satisfaction with the service.
b. Care burden – The Zarit Burden Interview is not specific to dementia care but is the most widely used tool. It has been validated in a number of CALD groups and comes in a variety of lengths from 4 questions to 29.

c. Carer ways of coping and coping strategies.

d. Carer knowledge.

e. Carer self efficacy.

A review of the carer outcome measures can be found in Sonsoni et al (2007) pages 332-351. Another list of carer assessment scales that are used in dementia care can be found at: [http://www.dementiacoalition.org/pdfs/ca_grid.pdf](http://www.dementiacoalition.org/pdfs/ca_grid.pdf)

Outcome Measures

References:


Driving and Dementia

Background

Driving is a complex, demanding, yet well learned task that relies on a multitude of cognitive, perceptual and motor abilities (Dawson et al, 2009). Dementia causes progressive impairment in many of the abilities necessary for safe driving, for example, visuo-spatial skills, judgement, insight, reasoning, information processing speed and working memory. The effect dementia has on driving abilities is noticeable in the earliest stages of the disease. People with mild cognitive impairment and mild dementia make more errors when driving compared to their healthy peers (Dawson et al, 2009; Wadley et al, 2009), with those with dementia between 2.5 to 8 times more likely to crash (Man-Son-Hing et al, 2007). Despite this, many people in the earlier stages of the disease (up to 76%) remain safe to drive and should be afforded the opportunity to do so (Brown et al, 2005; Grace et al, 2005; Ott et al, 2008).

Losing the right to drive is a serious issue with enormous impacts. Losing the right to drive has been linked with increases in depression (Marottoli et al, 1997; Ragland et al, 2005), loneliness, social isolation (Marottoli et al, 2000) and loss of independence (Carr, 2007). It results in increased stress on family and friends and an increased likelihood of placement into residential aged care (Freeman et al, 2006). The risk of these effects is greater for those residing rurally. (Man-Son-Hing et al, 2007 – see p. 878 for all the refs for this). Unfortunately, people with dementia may not always recognise their deficits in driving abilities and may have difficulty altering their behaviour and solving problems quickly as they arise during driving. Up to 25%-33% continuing to drive even after being told to stop (Dickerson et al, 2011; Seiler et al, 2012). Some people (10%) with dementia resort to using co-pilots (Foley et al, 2000) when driving, often to assist with way finding (Shua-Haim et al, 1999).

Driving and Dementia Types

Most of the research on driving in dementia has concentrated on Alzheimer's disease. The highest rate of driving cessation is seen in Lewy body dementia, followed by vascular dementia (Seiler et al, 2012). The lowest rates of driving cessation is found in those with Alzheimer's and fronto-temporal dementia (Seiler et al, 2012). The most common errors displayed by those with dementia whilst driving are lane deviations followed by failures in lane checking and changing, blind spot checking, awareness of traffic, merging, making complete stops, unsafe turning, unsteadiness in steering and poor speed control, (Davis et al, 2012; Dawson et al, 2009).

Driving and mild cognitive impairment is an emerging area of research. People with mild cognitive impairment demonstrate more errors when making 'left hand' turns and in lane control and had lower scores in maintaining proper speed and gap judgement (Wadley et al, 2009). Their errors may initially be benign and subtle before progressing to be more problematic and overt.
Driving abilities in those with HIV related cognitive impairment has highlighted changes in visuo-spatial and attentional abilities which may predict unsafe driving performance (Foley et al, 2013).

For more detailed explanation about the impact dementia has on driving from a pathophysiological perspective refer to Ott and Daiello (2010).

Indicators and risk factors associated with driving and dementia

Driving issues should be explored and assessed when a diagnosis of dementia or mild cognitive impairment is made (Breen et al, 2007). International consensus exists that it is not safe for those with moderate and more advanced dementia to drive. But it is widely accepted that whilst there is increased risk that those with mild cognitive impairment and mild dementia may be unsafe, many are safe to drive.

Considerable research has been conducted to identify indicators suggesting increased driving risk. Findings are summarised below:

- Clinical Dementia Rating Scale 0.5 to 1. Those with a CDR score of 0.5-1 may be at increased risk when driving but a systematic review found 41-85% were judged to be safe drivers (Iverson et al, 2010). A CDR score of 2 or more is indicative of high risks associated with driving.
- Timeframe since onset of dementia. Evidence suggests that driving risk remains relatively low for the first 3 years post dementia onset (Breen et al, 2007).
- Carer’s report that the person’s driving is unsafe or of concern. Breen et al (2007) suggest carers be asked about “driving the wrong way around roundabouts, getting lost in familiar areas, miscalculating speed and distances and poor judgement” (p1366-67). They may not necessarily provide accurate reports if they hold ulterior motives. This is particularly the case where they are dependent on that person for transportation or where they are concerned about the ramifications of disclosing risk issues. Adler et al (2000) reported ‘20% of caregivers who were dependent on a driver with dementia believed that the driver should limit or discontinue driving, compared to 87% of caregivers who were not dependent on the driver with dementia.’ Iverson et al (2010) have developed a questionnaire that can be administered to families or carers.
- History of traffic offences and crashes. Some studies have found that those with dementia have a higher crash rate and higher rate of it being their fault (Breen et al, 2007; Man-Son-Hing et al, 2007).
- Reductions and/or avoidance in driving. Self limiting driving can be an indicator of that the person is experiencing increasing difficulty driving. A questionnaire about driving history and competence for people with dementia can be found in Iverson et al (2010).
- MMSE score. MMSE score is not seen as a strong indicator of driving ability. Some studies have suggested a score of 24 or below as indicative of increased driving risk (Iverson et al, 2010), whilst other studies have found that those with an MMSE score of 22 or below consistently failed driving tests (Shuaa-Haim & Gross, 1996).
• Being male. Women with dementia have the highest probability of ceasing driving (Seiler et al, 2012).
• Aggression or impulsivity.
• Visuo-spatial deficits. An on road driving assessment is suggested for those with mild cognitive impairment and mild dementia who display visuo-spatial deficits.
• Comorbidities and drug use. Alcohol use, some medications (in particular psychotropics), sleep apnoea, cardiovascular disease, visual and hearing impairments and impairments in motor abilities, e.g. arthritis can impair driving abilities and should be screened for (Australian and New Zealand Society for Geriatric Medicine, 2009; Iverson et al, 2010; Rapoport et al, 2008).

Legal Requirements

Drivers who are diagnosed with dementia are required to advise the licencing authority in their state (Austroads, 2012). When a diagnosis of dementia is given, the health professional should advise the person of their duty to inform the licencing authority. Consideration should be given to reporting the person directly to the licencing authority where the person is:

• “Unable to appreciate the impact of their condition, or
• Unable to take notice of the health professional’s recommendations due to cognitive impairment, or
• Continues driving despite appropriate advice and is likely to endanger the public” (Austroads, 2012, p8).

Relationship between cognitive tests and driving skills

Cognitive and functional tests have received increasing attention in an effort to explore their predictive relationship with driving abilities in those with dementia. Global cognitive measures like the MMSE have been found to correlate with difficulty in driving tasks but are have not successfully predicted driving capacity. Short term memory tests have not been found to be a good indicator of driving abilities.

Tests of executive functions and visuo-spatial skills are increasingly receiving attention. A meta analysis of studies examining the relationship between neuropsychological functioning and driving abilities in those with dementia found that impairments in visuo-constructional skills best predicted reductions in driving ability with attentional deficits mildly related (Reger et al, 2004). Tests that have been investigated as predicting driving ability include: the clock drawing test, Trail making test, Porteus mazes, usual field of view, driving scenes test of the Neuropsychological Assessment Battery. For a review of the tools in this area see Brown & Ott, (2004) and Virkljan et al (2011). Ott and Daiello (2010). Visuo-spatial skills are necessary for

Lincoln et al (2006, 2010) developed a formula based on a combination of 6 neuropsychological subtests. It reliably detects 76% of safe drivers and remains a work in progress.
A significant relationship has been found between impaired process skills and driving abilities. Scores on the Assessment of Motor and Process Skills test have successfully predicted whether drivers passed, failed or required a restricted licence (Dickerson et al, 2011).

Assessing Fitness to Drive

Occupational therapy driving assessments are the gold standard for assessing fitness to drive. These tests comprise off and on road assessments and may result in licence cancellation, licence restrictions or no changes at all. On road tests conducted in the person’s usual environment have been found to be equally effective in assessing fitness to drive as formal road test routes (Davis et al, 2012). A recent Cochrane review failed to find any evidence that driving assessment processes support people with dementia to continue driving safely (Martin et al, 2011).

Strategies supporting driving cessation

There is increasing consensus that driving cessation should be a plan for older people (Betz et al, 2013; Hogan et al, 2008). The majority (66%) of family and carers have spoken about driving cessation with the person with dementia (D’Ambrosio et al, 2009). Despite this high rate of discussion, this does not necessarily translate into a plan of action. Furthermore, over one third of family and carers felt the person with dementia would know when it was time to cease driving.

There are a number of strategies suggested for supporting driving cessation or limiting driving (Byszewski et al, 2010; Perkinson et al, 2005).

1. Raise the prospect of driving cessation as early as possible in the diagnosis process.
2. Solicit the family’s support and consistency. Have them provide the person with dementia with feedback about their driving.
3. Provide the family with education to assist them in understanding the need for driving cessation. If needed have the family experience driving with the person with dementia.
4. Provide evidence of the need to cease or limit driving.
5. Remove the driving opportunity.
6. Recognise the symbolism and support this. For example, by allowing them to keep the keys but ensuring they will or can no longer drive.
7. Find substitute activities and alternate transportation.
8. Providing a written letter explaining why cessation is required.
9. Refer the person for a second opinion.
10. Report the person to the relevant authority.
Supporting Safe Driving in Dementia

Treatments to support those with dementia to continue to drive or improve their driving abilities are very limited. Treatment with a cholinesterase inhibitor has improved some driving functions in two studies involving people with Alzheimer's disease (Daiello et al, 2008). Changes included improvements in maintaining lane position, overall response time and reduction in distractibility. Individuals with mild Alzheimer's disease who respond very well to 'anti-dementia' drugs should be given opportunity to prove their driving ability if this has been removed from them.

Physical activity has shown some benefit to driving performance in one study (Marmeleira et al, 2009). Improvements were observed in reaction time, movement time, response time, visual attention, speed of processing and divided attention.

Regular reviews at 6 monthly intervals are suggested by the Australian and New Zealand Society for Geriatric Medicine (2009) for people with dementia who are driving.
Driving and Dementia

References:


Cognitive Dementia and Memory Service (CDAMS)

Literature Review


Ragland, DR., Satariano, WA. & MacLeod, KE. (2005). Driving cessation and increased depressive symptoms. The Journals of Gerontology Series A Biological Sciences Medical Sciences, 60, 399-403.


Advance Care Planning

Advance care planning (ACP) enables people to indicate their future health care wishes and personal preferences, should their health deteriorate and they no longer have the capacity to make these decisions (Dening et al, 2011; Department of Health, Victoria). ACP may include arranging an Enduring power of attorney (Medical Treatment), an Enduring Power of Guardianship, or advance health care directives to refuse particular types of medical interventions, such as resuscitation or those which prolong life. The benefits of ACP include increased satisfaction of patients and their families, and reduction of stress, anxiety and depression in family members (Azoulay et al, 2005; Detering et al, 2010; Lautrette et al, 2007; Tinden et al, 2001; Wright et al, 2008). Medical events and changes in financial and living situations are often the precipitants for discussion about the subject of end of life care.

The importance of ACP in improving the end of life care of those with dementia is receiving increasing international recognition (Dening et al, 2011). Dementia is a terminal illness that irreversibly and progressively impairs skills necessary to make and communicate decisions about care preferences. Having an advance care plan in place ensures that the person’s preferences for end of life care are followed, even in the face of declining capacity. Linger et al (2008) found that whilst the majority of people had a Durable Power of Attorney (65%) and Living Will (56%), a substantial number did not. People of Anglo Saxon background, with higher levels of education and who are older, are more likely to have an advance care plan (Linger et al, 2008; Triplett et al, 2008).

People with dementia into the moderate stages are capable of participating in advance care planning discussions. Research suggests that a MMSE score of 18 to 20 is the threshold necessary for making informed decisions about end of life care preferences (Fazel et al, 1999; Gregory et al, 2007), though this is not widely accepted and capacity should be assumed unless there is evidence to suggest otherwise. However, the earlier in the disease trajectory an advance care plan is made, the more likely the person is able to meaningfully participate in the process (Dening et al, 2011). As cognitive impairment increases, engagement of caregivers in decisions about end of life care preferences increases substantially (Hirschman et al, 2004) and the likelihood of the person or their carer selecting life enhancing treatments also increases (Fazel et al, 2000; Mezey et al, 1996). However, in the more severe stages of the disease, they are more likely to refuse life sustaining treatments.

Where end of life care wishes are not in place, family are often left to make the decisions (Haydar et al, 2004), with many unprepared to do so (Forbes et al, 2000). Discussion about end of life care issues has sometimes been avoided due to the concern that discussing these issues would distress the person with dementia. This concern has not been substantiated. In those with mild to moderate dementia, discussing end of life care has not been found to be distressing (Finucane et al, 1991). Moderate levels of agreement have been found in end of life care wishes between the person with dementia and their spouses (Ayalon et al, 2012). But, families are...
more likely to select treatment, particularly when feeling burdened (Hirschman et al, 2004; Mezey et al, 2000). Support, information and education for families on dementia and its trajectory has been highlighted as assisting them in making end of life care decisions (Davies & Nolan, 2004; Ryan & Scullion, 2000).

Health professionals have a vital role in facilitating advance care planning discussion with persons with dementia and their family/carers (Dening et al, 2011). Assessment and diagnosis of dementia or mild cognitive impairment within a memory clinic has been cited as an opportune and important time for advance care directives to be discussed, as with time, the person's abilities to make these decisions declines (Hamann et al, 2011; Okonkwo et al, 2008; Wain et al, 2009; Wald et al, 2003). Laakkonen et al (2008) reported that 59% of caregivers would have liked to have discussed advanced care planning at diagnosis but only 6% had the opportunity to do so. Inaction of health professionals has been identified as a barrier to advance care planning (Cavalieri et al, 2002; Rurup et al, 2006). In addition to facilitating discussion about advance care planning and the values of the person, health professionals hold responsibility for assessing the person's competence and ensuring they are fully informed about the options associated with the decisions they are making (Silvester & Detering, 2011). Building the capacities of health professionals to discuss end of life care planning with those with dementia early on in their diagnosis has been highlighted (Gessert et al, 2000-2001; Sachs et al, 2004; Seymour et al, 2010).

Finally, ethical debate continues about the validity and effectiveness of advanced care directives in dementia care (de Boer et al, 2010; Hamann et al, 2011). Issues may arise when a person with more advanced dementia, deemed incompetent, may request treatment options that differ from that which they provided in their end of life plans (de Boer et al, 2010). Finally, some studies have found that the medical judgements of health professionals and perspectives of the family, often override those documented in an advance care plan (The et al, 2002).

Respecting Patient Choices is a model of advance care planning for patients, their families and health professionals in Australia. See: http://www.respectingpatientchoices.org.au/ Advance care planning documents and forms may be downloaded from the Respecting Patient Choices website. Respecting Patient Choices also provides education for health professionals.

Future Care Planning

Encouraging a person who is diagnosed with a progressive illness to make plans for how they would like to spend their time is part of good clinical practice. Future care planning is referred to a number of times in the dementia diagnosis literature, but little has been specifically written on the topic and the term is often used interchangeably with advance care planning (Carpenter et al, 2008; Derksen et al, 2005, 2006; Lin et al, 2005; Mate et al, 2012; Robinson et al, 2011). Future care planning arrangements include advance care planning in addition to arranging an Enduring Power of Attorney (Financial) and a wills. One study reported that future plans tended to be formulated following diagnosis, with plans being made at 10 weeks following diagnosis (Derksen et al, 2005).
Two areas of emerging evidence associated with future care planning included:

- GPS tracking. GPS tracking should be discussed as soon after diagnosis as possible to obtain consent from the person with dementia concerning their desire to use this technology in the future (Landau et al, 2010).
- Planning for driving cessation (Hogan et al, 2008). Driving cessation plans should be included as part of the advanced driving directive. Advance Driving directives would assist in prompting discussion and planning for driving cessation (Betz et al, 2012; Betz et al, 2013).
Cognitive Dementia and Memory Service (CDAMS)

Literature Review

Advance Care and Future Care Planning

References:


Literature Review


Telehealth

Telehealth involves the use of information technology mediated communication to deliver health services. Technology used may include using telephones, e-mail, video conferencing, software applications such as Skype, smart phones and electronic transfer of files. It is becoming far more commonplace in the delivery of health services.

In dementia care, telehealth has been used in the areas of patient diagnosis (Azad et al, 2012; Barton et al, 2011; Loh et al, 2005; Morgan et al, 2011; Martin-Khan et al, 2012; Moore et al, 2009), treatment and monitoring (Lee et al, 2000; Poon et al, 2005) and in educating and supporting the patient and/or their family/caregiver (Brennan et al, 1992; Glueckauf & Loomis, 2003; O’Connell et al, 2013). This review focuses on the use of telehealth in the assessment and diagnosis of dementia, in particular the use of video conferencing.

Telehealth in the diagnosis of dementia is an emerging field. It has evolved in an effort to address several needs:

1. It allows people, living in rural and remote locations, who are separated by distance from health professionals, to access dementia diagnostic services in a timely manner and without the cost, inconvenience and time associated with travel (Azad et al, 2012).
2. It allows specialist assessments to be completed where they would otherwise be unavailable or there would be significant delays in accessing them.
3. It may provide economic benefits compared with face to face service models.

The majority of studies on diagnosis of dementia reported using video conferencing technology. This technology was preferred, as it allowed real time communication between the health professional and person being assessed (Timpano et al, 2013).

To date, most studies have focussed on:

1. Determining the feasibility of using video conferencing to provide dementia diagnostic and treatment service.
2. Establishing levels of agreement between diagnoses given using videoconferencing versus face to face assessments.
3. Validating the administration of particular tests e.g. MMSE
4. Determining the acceptability of using video conferencing to provide dementia diagnostic and treatment services.

Feasibility of Dementia Diagnostic Services Using Video Conferencing

Barton et al (2011) studied the feasibility of providing memory clinic services to 15 American veterans referred to the service. Using video conferencing, the physician collected an informant interview, the person's medical history and history of cognitive complaint, and completed a behavioural assessment, functional assessment, a neurological assessment (with assistance from a remote clinician) and administered a comprehensive neuropsychological test battery (also with assistance from the remote clinician). Feedback about diagnosis was provided in a separate session, to which the person's GP was also invited. They found that it was feasible to
provide a memory clinic service using video conferencing. However, strict screening was required to remove persons with hearing or visual impairments, or who had a MMSE score below 12 or did not have a caregiver/family member to provide an informant history.

Another study examining the feasibility of a telemedicine memory clinic was conducted by Azad et al (2012). They found that the video conference sessions were feasible in providing follow up consultation to 99 older Canadians who had already been assessed on-site in a memory clinic. Physicians reported that the sessions provided enough information for clinical decision making (96%) and met the person's needs (96%).

The feasibility of diagnosing Alzheimer's disease in Americans with Down syndrome has also been studied (Lott et al, 2006). Ninety people who were screened as meeting the criteria for dementia using the Dementia Questionnaire for Mentally Retarded Persons (Evenhuis, 1996) were assessed either using video conferencing or face to face consultation. They found it was possible to make a diagnosis and an independent neurological diagnosis supported the findings from the imaging, neurological and neuropsychological tests.

Finally, video conferencing has been used to assist with dementia diagnosis in third world countries. Skype was used in a tele-psychiatry pilot project in Somaliland where 132 people with suspected psychiatric disorders including dementia were assessed and diagnosed by Somali psychiatrists located in Scandinavia (Abdi & Elmi, 2011).

**Accuracy of Dementia Diagnosis**

Shores et al (2004) compared face to face versus video conference geriatrician consultation for 16 American residents of a Veterans home. Prior to assessment, a neurological evaluation, pathology tests, medical history, MMSE and Lawton-Browdy instrumental activities of daily living and physical self maintenance scale were completed. The face to face and video conference assessment involved a structured psychiatric assessment, focal neurological tests and cognitive testing (short Blessed, three word recall and clock drawing). There was 100% agreement in dementia diagnoses between the two mediums.

In another study comparing diagnosis of Alzheimer's disease in 20 older rural Western Australians by face to face versus video conference, sensitivity and specificity of 90% and 100% was established (Loh et al, 2005). Diagnosis was based on Standardized Mini-Mental State Exam (SMMSE), Geriatric Depression Scale (GDS), Katz Activities of Daily Living (ADL) assessment, Independent ADL assessment, Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE), clinical history, examination and investigations.

A more recent study by the same research group found high levels of agreement in dementia diagnosis in 205 Western Australians and Queenslanders who were randomly allocated to receive either two face to face assessments or a face to face, and video conference assessment by two independent memory disorder specialist physicians (Martin-Khan et al 2012). All were initially assessed by a clinic nurse who administered the following cognitive assessments: SMMSE, Rowland Universal Dementia Assessment Scale (RUDAS), clock face test, letter naming verbally fluency test, naming animals verbal fluency and the GDS; while a second clinician met with their carer and administered the IQCODE, Neuropsychiatric Inventory-short form (NPI-Q)
and Disability Assessment for Dementia (DAD). Disagreement between raters mainly occurred when one diagnosed mild cognitive impairment and the other Alzheimer's disease and/or vascular dementia. Disagreement was not predicted by type of dementia diagnosis.

Martin-Khan et al (2009) found similar levels of agreement in depression diagnosis through video conferencing (79.3%) and face to face consultation (76.7%) in 155 older persons accessing memory disorders clinics.

Accuracy of Cognitive Tests

The validity of administering cognitive assessments using video conferencing has been studied. Loh et al (2004) examined the interrater reliability of the Standardised Mini-Mental State Exam (SMMSE) and Geriatric Depression Scale (GDS) administered via video conferencing and face to face to 20 geriatric hospital patients in Western Australia with varying diagnoses (normal, dementia & depression). They found a 90% and 78% correlations between SMMSE and GDS scores respectively. Some variation in test scores can be attributed to repeated administration. The MMSE has 85%, 90% and 58% correlations in repeated same day administration to people who are cognitively normal, have dementia or delirium respectively (Anthony et al, 1982). Delirium in some of the patients was another identified likely contributor to the variation found in this study. Preferences of persons tested to either video conferencing or face to face assessment may also have been a contributor.

Accuracy of the MMSE was also examined by McEachern et al (2008) with 71 older Canadians who had attended a rural and remote memory clinic. They found no significant difference in MMSE scores administered in face to face and video conference consultations.

The accuracy of a range of cognitive tests were tested by Cullum et al (2006) on 14 people with mild cognitive impairment and 19 people with mild to moderate dementia via video conferencing and face to face. They very showed high to strong levels of agreement in scores of the following tests: MMSE (88%), Boston Naming Test (87%) and letter fluency (83%), digit span recall (78%), and Hopkins Verbal Learning Test-Revised (HVLT-R) total recall (77%). Moderate levels of agreement were found in the HVLT-R tests of recognition (68 %) and delayed recall (61%). The agreement in verbal percentage retention on the HVLT-R was lowest (54%) with scores found to be higher during the face to face assessments. The clock drawing test was not found to be reliable.

The Rowland Universal Dementia Assessment Scale (RUDAS) was administered to 42 patients of a Geriatrics and Rehabilitation Unit both using face to face and video conferencing (Wong et al, 2012). There was no significant difference in test scores between the two modes of administration. The test can be used to screen for dementia using videoconferencing with a cut off score of 23.

Finally, the reliability of the CAMDEX has been assessed in a small study involving 8 older English people (Bell et al, 1998). They found the CAMDEX could be administered via video conferencing in a reliable manner without any modification.
Acceptability of Dementia Diagnostic Services Using Video Conferencing

The acceptability of the use of telehealth by service providers and users is necessary to ensure it is well utilised. Azad et al (2012) found that 'over 90% of physicians and patients were willing to use video conferencing again'. Older people (100%) reported that they would prefer using video conferencing over travelling (Barton et al, 2011; Fredricks et al, 2008; Shores et al, 2004), that they would use it again (Morgan et al, 2011; Shores et al, 2004) and 99% would recommend it to another person (Morgan et al, 2011). Acceptability has also been studied in other cultures, with high levels of acceptability found amongst older American Choctaw Indians, only 3% not showing up for video conference appointments and 2 persons refusing follow up appointments (Weiner et al, 2011). Increased anxiety has been reported in association with video conferencing and some people would have preferred a face to face review (Azad et al, 2012; Morgan et al, 2011).

Discontinuance of memory clinic follow up through video conferencing was higher among older people and in those who had to travel more than 100km to access the service (Morgan et al, 2011).

Challenges and Recommendations with Using Video Conferencing to Diagnose and Treat Dementia

Use of video conferencing to diagnose and treat dementia is not without its challenges. The main challenges are summarised as follows:

1. Technology requirement: For video conferencing, fast and secure connections between the patient and the health professionals are required. Some large geographic areas that use telehealth widely, have dedicated video conferencing facilities and networks that are secure, and ensure patient privacy is protected. Technical difficulties such as picture freezing, audio quality and signal drop out were commonly cited issues (Azad et al, 2012; Fredricks et al, 2008; Loh et al, 2004; Lott et al, 2006; Shores et al, 2004). High speed connection, high picture resolution with high number of picture frames per second, are necessary to maximise flow of information, and ensure smooth, uninterrupted audio and visual connection between the memory clinic health professional and patients/families. A minimum bandwidth of 384 kbps has been recommended (Martin-Khan et al, 2012; Ramos-Rios et al, 2012). Concerns about privacy have been documented (Timpano et al, 2013). The Australian Medical Association states that "It is mandatory for all medical practices integrating electronic communications to ensure they are compliant with appropriate standards around hardware and software, and secure transmission of data, including authentication" (AMA, 2006).

2. Type of set up: Access to several camera positions which the assessing physician or health professional could control has been suggested (Weiner et al, 2011). This would allow them to access additional visual information which may not be readily seen using the primary camera position. Having a remote clinician or technician set up, ensure the person is correctly positioned in front of the video camera, explain how to the use the
video conferencing facilities and act as a trouble shooter throughout the ‘visit’, has also been recommended.

3. Physical contact during assessments: Completing some aspects of a physical and neurological examination which are standard practice in dementia diagnosis procedures cannot be done in the absence of touching the person. Furthermore, some neuropsychological and cognitive tests require a tester to provide or position items in a standardised manner. These challenges were addressed in several different ways. Trained staff located at the patient’s end of the video conference were used in many of the studies (Barton et al, 2011; Lee et al, 2000; Lott et al, 2006; Martin-Khan et al, 2012; Weiner at al, 2011). Loh et al (2004 & 2005) relied on GPs to complete the physical exams. Martin-Khan et al (2008) found that diagnoses of dementia did not change after the physical examination of 28 out of 30 older people and so concluded, that a physical examination makes little difference to the diagnosis of dementia, except possibly in the case of vascular dementia. Finally in response to the need to have a person directly deliver standardised tests, Cullum et al (2006) suggest incorporation of computer based cognitive tests.

4. Sensory impairments: Persons with hearing or visual impairments were identified in a number of studies as being unsuitable for dementia assessment through video conferencing (Azad et al, 2012; Barton et al, 2011; Morgan et al, 2011; Ramos-Rios et al, 2012).

5. Individual preferences. Some people may be less likely to disclose symptoms when engaged in a medium with which they are less comfortable and may become more anxious. Conversely, some may be more likely to be involved in a video conference assessment due to novelty. Level of participation and motivation may also differ depending on the individual’s preferences (Cullum et al, 2006; Loh et al, 2004; McEachern et al, 2008).

6. Medico-legal issues. The Australian Medical Association has released a position statement on on-line and broadband connected medical consultations (2006). They do not support the use of telehealth where the patient does not already have a relationship with the physician. “The only exceptions should be where there is no practical alternative available, for example, ...where it provides access to medical services in areas where such services would otherwise be unavailable” (AMA, 2006). Protocols should be established to guide telehealth practices and the services should be “underpinned by signed patient agreement to strict written terms and conditions for eligibility to use, that also outline the limitations on the type of care that will be provided...and the right of the doctor to determine whether the provision of any advice or care through such a system is appropriate” (AMA, 2006).

7. Some small differences exist in the diagnoses given during face to face versus video conferencing. This has implications for prescriptions of medication, particularly cholinesterase inhibitors and antidepressants (Loh et al, 2004).

8. Severity of impairments: Video conferencing assessments require the person to be cognitively able to participate in an interview and assessment. Reference has been made to video conferencing only being suitable for people with MMSE scores of 12 or above (Barton et al, 2011; Weiner et al, 2011). But, little reference has been made to
difficulties that might arise for those with speech and communication disorders (Barton et al, 2011).

9. Culturally and linguistically diverse groups: None of the studies examined assessment of persons who did not speak English. Consequently the reliability of video conferencing to deliver assessment services to those with possible cognitive impairment requiring interpreting services, has not been examined.

10. Neuropsychiatric disorders: Diagnosing neuropsychiatric disorders may be more difficult using video conferencing, particularly in the absence of well trained remote clinicians (Barton et al, 2011).
Cognitive Dementia and Memory Service (CDAMS)

Literature Review

Telehealth

References:


Cognitive Dementia and Memory Service (CDAMS)

Literature Review


Wong, L., Martin-Khan, M., Rowland, J., Varghese, P. & Gray, LC. (2012). The Rowland Universal Dementia Assessment Scale (RUDAS) as a reliable screening tool for dementia when