Bridging the gap in YOD diagnosis, care

BRIGHT-YOD is a new and innovative telehealth project designed to improve access to specialist diagnosis and care and reduce costs for people with younger onset dementia (YOD) across Victoria, particularly in regional and rural areas. **Sarah Farrand, Wendy Kelso, Stefanie Colella, Melinda Sorraghan** and **Dennis Velakoulis** explain how the project is tackling the specific challenges faced by people with YOD

Dr Wendy Kelso (front left) and Dr Sarah Farrand (front right) with (on screen) social worker Jacinta Flood (left) and neuropsychologist Dr Deborah Goff, from the Albury Cognitive Dementia and Memory Service, during a BRIGHT-YOD telehealth meeting.

Photos: Melbourne Health

Younger onset dementia (YOD) is a debilitating terminal illness, with dementia onset prior to 65 years of age. It affects approximately 25,000 Australians and makes up 10% of all dementia cases (Brown *et al* 2017). While dementia is a National Health Priority Area, people with YOD fall through clinical service gaps and struggle to access the highly specialised expertise required to diagnose and manage their unique sets of needs.

Diagnostic delay is common in those experiencing YOD, taking on average two to four years to reach a diagnosis (Van Vliet *et al* 2013). A diagnosis of YOD can result in up to 20 years of life lost (Brodaty *et al* 2012) with multiple and complex presenting features requiring specific expertise for diagnosis and care. The spectrum of disorders causing YOD is broad, from conditions such as Alzheimer's disease and frontotemporal dementia, through to very rare disorders such as Niemann-Pick Type C. People with YOD and their carers face hurdles at all stages, including navigating employment, caring for school age children, financial and psychological stress, grief, and the prospect of facing a life-limiting, possibly hereditary illness.

Specific challenges

Delay in diagnosis

Despite the differing conditions which cause YOD, those experiencing it share common issues, particularly delay in diagnosis. A recent audit of 304 inpatients (2014-2017) from our service, the Melbourne Young Onset Dementia Service (MYOD) in the Neuropsychiatry Unit at Royal Melbourne Hospital, revealed that each person had seen an average of five specialists prior to referral, (without including general practitioners or allied health assessments), with a mean duration of symptoms of 5.6 years and mean diagnostic delay of 2.9 years, in keeping with worldwide estimates (Van Vliet *et al* 2013).

Timely diagnosis is crucial to ensure early intervention, adequate treatment and the ability to plan for the future. A delay in diagnosis can have wide-ranging consequences for the person with YOD and their family, including loss of employment and entitlements, increased carer burden, marital breakdown and significant psychological difficulties for affected children. The average life expectancy from onset of symptoms for YOD ranges from 1.3 years (ie for rapidly progressive illness such as frontotemporal dementia with motor neuron disease) to 7.9 years (Brodaty *et al* 2012). Given a diagnostic delay of up to and sometimes more than four years (Van Vliet *et al* 2013), the diagnosis is often made when there are few quality years left for the person with dementia and their carer/family unit.

Barriers to early diagnosis include difficulties accessing appropriate YOD services, a lack of medical awareness/confidence in diagnosing YOD, the broad range of aetiologies and the clinical overlap with psychiatric conditions. The initial symptoms of YOD are often changes in emotion, personality or behaviour, which are misattributed to a psychiatric condition, resulting in the person then being directed to psychiatric services (Van Vliet *et al* 2013).

Quality of life and carer burden

Individuals with YOD have markedly increased rates of anxiety and depression and significant reductions in quality of life. This is equally true for partners and carers. Recent assessment of quality of life of 69 YOD outpatients in our service using the EQ-5D-5L (a standardised instrument for measuring general health status), found a mean index of 0.551, indicating 2.75 Quality Adjusted Life Years (QALYs). Thus, if one presumed a further five-year life expectancy (where one QALY equates to one year of perfect health), these outpatients had only 2.75 years out of these five with good health. Prominent difficulties experienced by people with YOD, such as anxiety, depression and inability to work/drive, do not fit as well into support services or systems such as the National Disability Insurance Scheme. To the frustration of individuals and carers, their needs fall between service gaps – *"too young for some, too old for others, too complex for most"*.

Other issues faced by people living with YOD and carers include limited access to community care or meaningful activity, high levels of child, family and carer burden, the prospect of the illness being genetic and the significant lost productivity costs for the person with YOD and their carer. High levels of carer burden due to a lack of appropriate YOD specialist services, community day programs and specific respite options lead to crisis hospital admissions and earlier entry into residential care (Kane *et al* 2005).

Service access

Despite reporting high levels of carer burden, people living with YOD and carers under-use formal specialist services (Cations *et al* 2017). There are approximately 6213 people living with YOD in Victoria (Brown *et al* 2017), however actuarial estimates suggest that less than half of these will access YOD specialist services. Reasons for service under-use include (Cations *et al* 2017):

- Limited accessibility (distance/financial cost/loss of productivity/absence of childcare).
- Lack of appropriate services for younger people (education/support groups/planned activity groups/residential aged care facilities).
- Community awareness and stigma.

A recent review of YOD service access found that people with YOD and carers were calling for YOD specialist services that allow for tailored and timely intervention, flexible access, financial accessibility, case management and meaningful engagement (Cations *et al* 2017; Sansoni *et al* 2016). Centralised multidisciplinary care has been proven to confer a survival advantage for people with neurodegenerative illness and is superior to devolved community-based care (Rooney *et al* 2015).

The BRIGHT-YOD team (from left) Melinda Sorraghan, Dr Wendy Kelso, Stefanie Colella, Dr Sarah Farrand and Professor Dennis Velakoulis

YOD-specific factors impacting on access to care

Due to the degenerative nature of their illness, the majority of people living with YOD have cognitive and/or physical limitations that impact on their ability to travel to hospital appointments independently. Families with YOD face economic disadvantage due to loss of income both for the person with YOD and the carer/family unit if they are absent from work. Due to the younger age of the carers, work and childcare commitments can negatively impact on ability to attend medical appointments.

Enabling YOD-specific care

Telehealth has the potential to efficiently and effectively deliver specialist healthcare to those living in regional, rural and remote areas, as well as for those with impaired cognition, mobility and social isolation. Uptake of telehealth across Australia has soared in the past decade, with government data showing 1808 specialist services delivered via telehealth in the first quarter of the 2011-12 financial year, compared with 36,729 in the first quarter of the 2015-16 financial year. Psychiatry has thus far led the charge, with 39.5% of all specialist telehealth items billed in the 2017-2018 financial year, though this still makes up only 3% of all psychiatry consults (Department of Health n.d.).

Based on current service and prevalence data it's estimated that of the approximately 6000 Victorians with YOD, about 500 people are living in residential aged care facilities and may not be able to attend specialist clinics; approximately 500 individuals with YOD are managed by private practitioners (GPs, geriatricians, neurologists and psychiatrists) and up to 3000 people with YOD are not attending specialist YOD clinics, suggesting substantial unmet need and service under-use.

Analysis of service data from the Neuropsychiatry Unit's MYOD Service over a 12-month period (2017-2018) revealed that 130 (37%) individual outpatients and 47 (49%) inpatients were from outside a major city. For the rural and regional Victorian outpatients, the average distance travelled was 269km (for those travelling more than 50km). Interstate outpatients travelled on average 540km. To translate this to travel and lost productivity costs for a person with YOD/carer attending from a distance less than 50km this equated to $257 per visit; between 50-100km, $455 per visit; and greater than 100km, $633 per visit.

The BRIGHT-YOD Project

Given the projected unmet need in a relatively small state such as Victoria, and the significant costs to people living with YOD and carers, the BRIGHT-YOD project was launched in Victoria on 1 April 2019 to improve access to diagnosis and care for those with possible younger onset dementia, whilst reducing costs associated with accessing specialist clinics. BRIGHT-YOD (Bridging Gaps in Health using Telepsychiatry for Young Onset Dementia) is a collaboration between the MYOD Service based in the Neuropsychiatry Unit at Royal Melbourne Hospital, four Cognitive, Dementia and Memory Services (CDAMS) (Ballarat, Shepparton, Albury-Wodonga and Royal Melbourne Hospital), Huntington's Victoria and Dementia Australia.The MYOD Service is one of the few services nationally that can provide tailored, flexible and expert services to those affected by YOD. The project is funded and supported by Better Care Victoria, a branch of the Department of Health's Safer Care Victoria.

Services offered through the project include: neuropsychiatric and neuropsychological assessment, primary or secondary consultations, second opinions, education and carer/client support. Video interpreting services are also available.

The aims of this project are to:

- Further assess and understand the needs of people living with YOD and families, and the unmet need across Victoria.
- Increase access to YOD-specific care (including diagnosis and ongoing management).
- Reduce costs for people with YOD and carers in accessing YOD-specific care.
- Partner with rural care providers, including CDAMS, Dementia Australia and Huntington's Victoria, and deliver capability-building sessions for these multidisciplinary teams.
- Assess and improve quality of life, and burden of

illness/caring for people with YOD and carers.
- Formally assess the cost-effectiveness of this telehealth service.

Early outcomes and learnings

Since the BRIGHT-YOD project went live on 1 April 2019 there have been 13 people seen as part of the pilot implementation. Whilst more data is required to assess the overall aims and outcomes of the project, there have been over 7600km saved for clients and their families with over 1.9 tonnes of carbon emissions saved.

Of particular value to the project team has been the involvement of people with YOD and families through participation in a focus group and as members of the project steering committee. Themes that have emerged from this have included:

- The need to offer telehealth and face-to-face contact as a choice to those being referred to the service – not assuming that people may want one or the other.
- Being mindful of delivering diagnoses via telehealth. Those who lived closer to major metropolitan centres felt more likely to want to do this face-to-face, whereas those who were a three- or four-hour drive away felt telehealth would be more acceptable for delivering diagnoses, but may wish to have these appointments at their GP clinic rather than home, to enable more professional support face-to-face if required.
- Considering terminology: as health professionals, we may refer to those using the service as our 'patients' and their spouse, children, neighbours etc their 'carers', but these are terms that our clients may not identify with and, in fact, may reject. People felt that they entered a diagnostic assessment as partners, competent workers, parents and the like, and came out as a 'patient and carer' even though they didn't feel any different than before the appointment.

Our other learnings from interactions with colleagues and clients, attending telehealth conferences, and learning from enthusiastic telehealth teams, have been that whilst clinicians may feel that telehealth is 'less than' or that they can't offer the same care, clients are often very satisfied with this option. Whilst clinicians may feel they have to work harder to develop rapport, and do things slightly differently to normal (ie arranging tests in the person's local area), clients can feel empowered and like the fact that there is a 'levelling of the playing field', or that they can undertake cognitive assessment in the comfort of their own home, which reduces their anxiety.

Client feedback

Regarding the use of telehealth: "It was a great benefit as we have had extreme difficulty getting [person with YOD] to attend any of his appointments. This was a great option for us."

Perceived benefits include: "Travel, accommodation costs, time on roads, embarrassment, food, fuel, frustration, anger. The list could be endless depending on the road and weather conditions."

Challenges

The challenges are both the expected, such as internet connection difficulties, overcoming health service firewalls, and rescheduling appointments when things do not go to plan; and the unexpected – the 'metrocentricity' of clinicians, assumptions that Victoria is a small state without a need for telehealth services, overestimation of clinical risk involved with undertaking telehealth consultations, or the view that telehealth consults can only be 'better than nothing' as opposed to equal or even preferable.

Future directions

Recent figures showed that psychiatry is leading the charge with telehealth, but there is still huge scope for incorporating telehealth into business as usual. The utility of telehealth is not just in enabling client-doctor interactions, but in facilitating case managers, care coordinators and distant relatives to join in important discussions, broaden multidisciplinary care planning, deliver education and many other areas. Critical to the development of telehealth services is the inputs of service users as well as considering the preference not only of rural clients but those in cities, where clients may still travel up to an hour one way to reach specialist appointments. For areas of practice such as YOD, where centralised specialist care is the gold standard, development of evidence-based telehealth models of care needs to be a priority in order to provide equity of access to all Australians. ■

Inquiries and referrals

For more information about the BRIGHT-YOD project and the MYOD Service, visit http://www.neuropsychiatry.org.au. For inquiries and referrals, email NPUReferrals@mh.org.au. A referral form can also be found on the website.

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References

Brodaty H, Seeher K and Gibson L (2012) Dementia time to death: A systematic literature review on survival time and years of life lost in people with dementia. *International Psychogeriatrics* 24(7) 1034-1045.

Brown L, Hansnata E and La HA (2017) *Economic cost of dementia in Australia 2016-2056*. Canberra.

Cations M, Withall A, Horsfall R *et al* (2017) Why aren't people with young onset dementia and their supporters using formal services? Results from the INSPIRED study. *PLOS ONE* 12(7) doi.org/10.1371/journal.pone.0180935.

Department of Health (n.d.) *Medicare benefits schedule statistics*. Department of Health. Available at: http://bit.ly/2H4MBDz.

Kane RL, Gaugler JE, Newcomer R *et al* (2005) Early community-based service utilization and its effects on institutionalization in dementia caregiving. *The Gerontologist* 45(2) 177-185.

Rooney J, Byrne S, Heverin M *et al* (2015) A multidisciplinary clinic approach improves survival in ALS: a comparative study of ALS in Ireland and Northern Ireland. *Journal of Neurology, Neurosurgery & Psychiatry* 86(5) 496.

Sansoni J, Duncan C, Grootemaat P *et al* (2016) Younger onset dementia: a review of the literature to inform service development. *American Journal of Alzheimer's Disease & Other Dementias* 31(8) 693-705.

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.