**Young-onset dementia and its difficulties in diagnosis and care**

**Commentary on “Time to diagnosis in younger-onset dementia and the impact of a specialist diagnostic service”**

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Around the globe, dementia affects an estimated 50 million people (ADI, 2020). Whilst the majority of people live with the most common type of dementia – Alzheimer’s disease dementia, around 38% live with a rarer type of dementia (based on UK data, Alzheimer’s Society, 2014). These include Lewy Body dementia, vascular dementia, and behavioural-variant fronto-temporal dementia, amongst others. Each different subtype comes with its own symptom profile. People with Lewy Body dementia have significant mobility problems (Fritz et al., 2016), whilst people with semantic dementia have language difficulties (Ellajosyula et al., 2020). As a result, people with different dementias have different needs.

Age can be another factor influencing the needs of people living with dementia (PLWD). Incidence rates of young-onset dementia (YOD) per 100,000 general population range from 11 to 25 in different age categories under the age of 65 (Garre-Olmo et al., 2010; Kvello-Alme et al., 2020). Receiving a diagnosis at a younger age can bring with it a different set of difficulties than getting a diagnosis in old age, not only for the PLWD but also for family members and friends. Most people are in employment, and may have caring duties or double-caring duties for both children and elderly relatives.

Even if people receive a diagnosis of YOD, services have been found not to be age appropriate in many instances (Cations et al., 2017; Mayrhofer et al., 2018), with post-diagnostic support often inadequate (Giebel et al., 2020). Services are not adapted to the needs of younger people who may wish to engage in active activities, such as walking or bowling, as opposed to engaging in sedentary activities, such as singing and bingo. As a result, people with YOD may not feel well placed in groups of people aged in their 70s and 80s. Moreover, as many people with YOD and their carers are still in employment, the timing of services also needs to be considered, as mid-week day-time groups might be less suitable. All these factors can contribute to why people with YOD and their carers do not access post-diagnostic support services, if they are aware of these (O’Shea et al., 2019). According to a recent study involving people with YOD and their carers, the ideal service should be “unique, flexible, affordable, tailored, and promoting meaningful engagement” (Cations et al., 2017).

Having access to these activities and services depends on receiving a diagnosis in the first place though. This can be very difficult. A person or their family members and friends might not attribute symptoms such as forgetfulness or behaviour changes as symptoms of dementia at the age of 35 or 50 for example (Rabanal et al., 2018). This can delay approaching clinical professionals to investigate the symptoms, and is an issue generally across dementia, as a recent systematic review has shown (Parker et al., 2020). Other barriers can be stigma and fear, lack of informal network support, and normalising symptoms. Even when consulting a clinical professional, such as a General Practitioner in the UK, they might equally not relate any symptoms and signs as indicative of dementia at such a young age. Draper and colleagues (2016) for example showed that the time from symptom onset to first consultation took an average of over two years, and the time from first symptoms to official diagnosis of YOD an average of five years.

In a recent study from Australia, Loi et al. (2020) retrospectively explored the predictors of delays in YOD diagnosis and the impact of a specialist YOD service on time to diagnosis. For this purpose, the authors consulted data from an inpatient unit of a tertiary neuropsychiatry service in metropolitan Victoria. Looking at various participant characteristics, including cognition and the number of services consulted pre-diagnosis, Loi et al. showed that the average time to diagnosis amongst over 200 people with YOD was 3.4 years. The younger people were, the longer it took them to receive a diagnosis. Moreover, if they had a dementia other than the most common YOD subtypes of Alzheimer’s disease dementia and behavioural-variant fronto-temporal dementia (Kvello-Alme et al., 2019), their diagnosis was delayed also. The more services that were consulted pre-diagnosis also increased the time to diagnosis. All these factors independently delayed the time between first symptoms and diagnosis.

Having a specialist YOD service however significantly reduced the time to diagnosis by 12 months. This is a significant reduction in time to diagnosis, which highlights the potential of providing more targeted support for people with YOD, and their carers. In particular, the service offers a 2-week inpatient assessment in an eight-bed facility, involving a broad assessment of biomarkers, neuropsychology, and other areas of health and psychiatry. Considering that a dementia diagnosis usually involves multiple appointments for brain scans, neuropsychological and -psychiatric assessments, as well as functional assessments, having a thorough assessment without the likelihood of missing appointments and additional travel appears to be a good solution. Moreover, the YOD service holds weekly team meetings to discuss cases, therefore enabling multi-disciplinary teams to meet and discuss and make decisions on cases swiftly.

It appears therefore that such a YOD-specific service would provide much needed reductions in the time to diagnosis. From a practical point of view however it is unlikely that such services will be implemented in each hospital / memory clinic assessment setting. This is just because of constant funding limitations and staffing issues. It is more likely, and recommendable based on these findings, to implement these services where possible, whilst simultaneously raising awareness of this specialist service with doctors who are in charge of referring patients for assessments. To ensure that each person has equal access to these services, awareness raising amongst healthcare professionals is vital, to enable the referral process to these specialised services.

This type of service might also be suitable for people with cognitive impairment. In a recent analysis of the diagnostic pathways for people with cognitive impairment (which is often a precursor for dementia), Black and colleagues (2019) reported delays in the time from initial symptoms to first consultation and diagnosis. Whilst these delays were not as severe as in YOD, delays in getting a diagnosis equally affect the ability of the health and social care system to support the person with cognitive impairment before further disease progression. This can also delay the necessary process of advanced care planning. Once a diagnosis is made, PLWD need to be supported to make decisions early on about their end of life care. Whilst this is often an additional stressful element surrounding the initial stress of receiving a diagnosis, it is important that PLWD are supported to make these decisions when they are in the early stages of the condition. For this reason, it is also important that diagnoses are made quickly, as someone who has experienced a delay of five years until the diagnosis is likely going to be in a more advanced stage with possibly less capacity to make these decisions. Informal and formal advanced care planning for dementia for example has been found to be high in a US sample (79%-87%), although more needs to be done to support people from any background, including ethnic background, to make these advanced decisions (Pettigrew et al., 2020).

The earlier someone receives a diagnosis of dementia, the better. Delays in diagnosis delay getting access to vital support services, from medical to non-medical support, with PLWD advancing further in their dementia. Not receiving suitable medication in time, such as donepezil (Birks & Harvey, 2018), will delay the window of opportunity to benefit the PLWD – receiving medication at an advanced stage will not be as beneficial as when receiving medication very early on, when people are still independent and thus can stay independent for longer. Therefore, it appears that YOD-specific services are one suitable solution to provide more timely diagnoses of YOD. Other solutions will be to provide more training to health care professionals about different types of rare dementias, which would also have an impact on people with late-onset dementia. Rarer dementias in general are not as easily diagnosed as Alzheimer’s disease dementia. By putting in place different strategies to support improved diagnosis of YOD, this might hopefully also have a domino effect on improving post-diagnostic care.

**Funding**

This commentary was supported by the National Institute for Health Research Applied Research Collaboration North West Coast (ARC NWC). The views expressed in this publication are those of the author(s) and not necessarily those of the National Institute for Health Research or the Department of Health and Social Care.

**References**

Alzheimer’s Disease International (ADI). From Plan to Impact III: Maintaining dementia as a priority in unprecedented times. London, England: ADI, 2020.

Birks JS, Harvey RJ. Donepezil for dementia due to Alzheimer’s disease. Cochrane Library 2018; doi: 10.1002/14651858.CD001190.pub3

Black CM, Woodward M, Ambegaonkar BM, et al. Quantifying the diagnostic pathway for patients with cognitive impairment: real-world data from Australia. International Psychogeriatrics 2019; doi: 10.1017/S1041610219001856.

Cations M, Withall A, Horsfall R, et al. Why aren’t people with young onset dementia and their supporters using formal services? Results from the INSPIRED study. PLOS One 2017; doi: 10.1371/journal.pone.0180935

Draper B, Cations M, White F, et al. Time to diagnosis in young-onset dementia and its determinants: the INSPIRED study. International Journal of Geriatrics Psychiatry 2016;31(11):1217-1224.

Ellajosyula R, Narayanan J, Patterson K. Striking loss of second language in bilingual patients with semantic dementia. Journal of Neurology 2020;267:551-560.

Fritz NE, Kegelmeyer DA, Kloos AD, et al. Motor performance differentiates individuals with Lewy body dementia, Parkinson’s and Alzheimer’s disease. Gait & Posture 2016;50:1-7.

Garre-Olmo J, Genis Battle D, del Mar Fernandez M, et al. Incidence and subtypes of early-onset dementia in a geographically defined general population. Neurology 2010;75(14):1249-1255.

Giebel C, Eastham C, Cannon J, et al. Evaluating a young-onset dementia service from two sides of the coin: staff and service user perspectives. BMC Health Services Research 2020; doi: 10.1186/s12913-020-5027-8

Kvello-Alme M, Brathen G, White LR, Sando SB. The prevalence and subtypes of young onset dementia in central Norway: a population-based study. Journal of Alzheimer’s Disease 2019;69(2):479-487.

Kvello-Alme M, Brathen G, White LR, Sando SB. Incidence of young onset dementia in central Norway: a population-based study. Journal of Alzheimer’s Disease 2020;75(3):697-704.

Loi S, Goh A, Maplas C, et al. Time to diagnosis in younger-onset dementia and the impact of a specialist diagnostic service. International Psychogeriatrics, 2020 in press

Mayrhofer A, Mathie E, McKeown J, et al. Age-appropriate services for people diagnosed with young onset dementia (YOD): a systematic review. Aging & Mental Health 2018;22(8):933-941.

O’Shea E, Timmons S, O’Shea E, Irving K. Multiple stakeholders’ perspectives on respite service access for people with dementia and their carers. The Gerontologist 2019;59(5):e490-e500.

Parker M, Barlow S, Hoe J, Aitken L. Persistent barriers and facilitators to seeking help for a dementia diagnosis: a systematic review of 30 years of the perspectives of carers and people with dementia. International Psychogeriatrics 2020; doi: 10.1017/S1041610219002229

Pettigrew C, Brichko R, Black B, et al. Attitudes toward advance care planning among persons with dementia and their caregivers. International Psychogeriatrics 2020;32(5):585-599.

Rabanal LI, Chatwin J, Walker A, et al. Understanding the needs and experiences of people with young onset dementia: a qualitative study. BMJ Open 2018; doi: 10.1136/bmjopen-2017-021166