YOUNG ONSET DEMENTIA:
thirty years of presentations to the National Memory Clinic

Martha Finnegan, Irene Bruce, David Robinson, Elaine Greene, MIRA, St James's Hospital, Dublin 8

Background

- Young onset dementia (YOD): onset at ≤ 65 years, rare and often life-limiting diagnosis [1
- Approximately 3-4000 people living with YOD in Ireland [2]
- YOD is associated with: longer time to diagnosis, wide range of underlying pathologies [2,3]
- Mercers Institute for Research in Ageing at St James's Hospital (MIRA) is a national, tertiary diagnostic memory clinic [4] All patients receive a comprehensive multidisciplinary assessment. Diagnoses are reached by consensus meeting (Neuropsychology, Neurology, Medicine for the Elderly and Psychiatry for the Elderly clinicians)
- Biomarkers (imaging, CSF analysis) increasingly used since 2015
- Patients with Mild cognitive impairment (MCI), are followed up in the clinic

Objective: This longitudinal service evaluation sought to describe the characteristics of people ≤65 presenting to the Memory Clinic over thirty years

Method

- MIRA database and patient records accessed following audit approval from R&I SJH
- All persons referred before their 66th birthday were identified
- Only persons with complete data were included in the analysis
- Consensus diagnoses were categorised into diagnostic groups
- Subgroup analysis of those with primary psychiatric illness, and those with mild cognitive impairment (MCI)
- Descriptive data analysis was conducted with SPSS v27, reported as mean (SD) unless non-normally distributed (median, range).

Results

- N=3689 attendances of n=2175 individuals were analysed
- Mean MMSE score:
- 1991 to 2019: 21.1 to 22.4, with SDs of 0.1 to 0.6
- 2020, 2021**: lower scores at presentation** (mean 21.03, SD 1.41; and mean 21.03, SD 1.25 respectively)
- Mean age at referral 58.34 (SD 6.4), stable over time
- Mean number of visits 1.69 (SD 1.1), range 0-11
- Mean time first visit to diagnosis 27.8 months (SD 26.2)
- Primary psychiatric illness accounting for memory problems (no dementia) in n=120 people, mean age of 55.9 (SD 6.9), primarily depressive (n=47), anxiety (n=49) and alcohol use disorders (n=10), Fig 2.

Mild Cognitive Impairment

N=681 people had MCI diagnoses at any time (amnestic; non-amnestic, or vascular) Mean follow-up period 29.4 months (SD 27.6): longer than total cohort

Mean age MCI diagnoses (single/first visit) 59.6 (SD 5.8): older than total

In MCI group, n=137 (20%) had final diagnoses of dementia after follow-up assessments, most commonly AD (n=97) or mixed dementia (n=22)

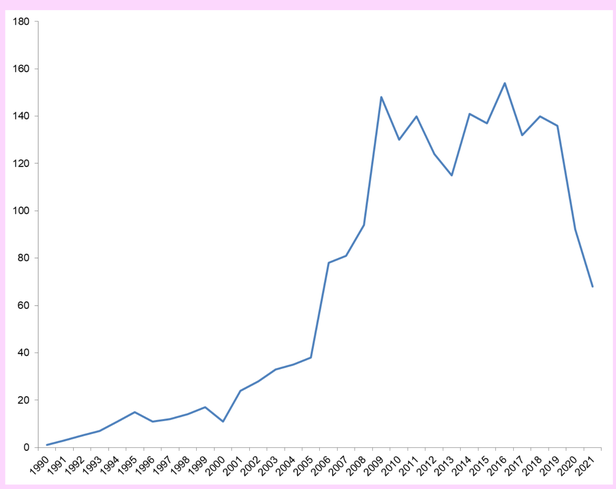

Fig 1. No. annual referrals ≤ 65 and acute drop during pandemic service restrictions

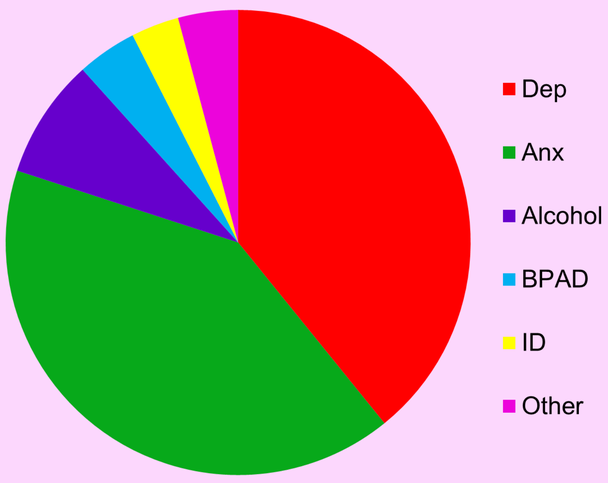

Fig2. Primary psychiatric disorders accounting for memory complaint, n=120

Fig 3. Diagnoses of n=2175 individuals assessed at MIRA from 1991-2021

Diagnosis	*Abbrev*	*N, % of total*
Subjective Memory Complaint	SMC	736 (33.8%)
Alzheimer's Disease Dementia	AD	409 (18.8%)
Amnestic Mild Cog Impairment	aMCI	226 (10.4%)
Unclear diagnosis	Unc	172 (8%)
Primary Psychiatric Illness	Psych	120 (5.5%)
Non-amnestic Mild Cog Impairment	naMCI	117 (5.3%)
Vascular Mild Cog Impairment	vMCI	112 (5.1%)
Frontotemporal Dementia (no subtype)	FTD	95 (4.3%)
Mixed Pathology (AD/Vasc) Dementia	Mix	69 (3.1%)
Primary Progressive Aphasia (FTD)	PPA	26 (1.2%)
Organic Amnestic Syndrome	Org	19 (<1%)
Vascular Dementia	VD	15 (<1%)
Dementia, subtype not elucidated	Dem	11 (<1%)
Lewy Body Dementia	LBD	8 (<1%)
Corticobasal Degeneration	CBD	8 (<1%)
Alcohol-related dementia (Korsakoff, Wernicke)	Alc	7 (<1%)
Semantic Dementia (FTD)	SemD	6 (<1%)
Posterior Cortical Atrophy	PCS	5 (<1%)
Transient Epileptic Amnesia	TEA	5 (<1%)
Parkinsons Plus Syndrome, undifferentiated	Park+	4 (<1%)
FTD with Motor Neuron Disease	FTDMND	3 (<1%)
Progressive Supranuclear Palsy	PSP	2 (<1%)

n=988 (45% of the sample) had subtype diagnoses with the following probable pathology:

1. **Amyloid disorders: AD, aMCI, PCS n=640),**
2. **Vascular pathology: VD, vMCI, Mix n=196**
3. **Tauopathies: FTD, CBD, PSP n=105**
4. **TDP-43 Pathology: PPA, SemD, FTD-MND n=35**
5. **α-Synucleinopathies: LBD, Park+ n=12 ***

*** α-Synucleinopathies in young people may be more commonly referred to Neurology services**

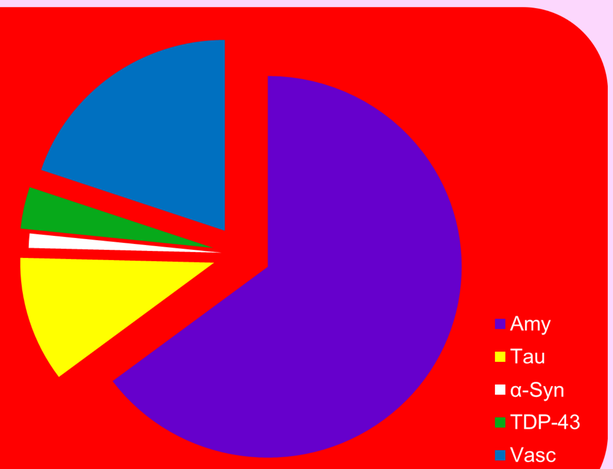

Fig 4. Probable pathologies of those with identified subtypes, n=988 (45% of total)

Conclusions

Results of this longitudinal service evaluation underline the wide spread of diagnoses (up to 15 per year), long time to diagnosis (28 months), and a growing national demand for assessment of people with possible YOD.

The majority of young people had established cognitive impairment on a screening instrument at first assessment (MMSE cutoff score of 23). Younger people presented with more severe memory impairment during the pandemic, possibly as a result of restriction-related assessment delays.

Identification of many rare subtypes of YOD in this cohort supports the National Dementia Strategy plan for specialised regional memory assessment services with access to biomarkers.

With thanks to our patients and to our past and present colleagues

References:
1.Fox, S. Cahill, S, McGown, R. and Kilty C. (2020) Young Onset Dementia: A Review of Diagnostic and Post-diagnostic Processes and Pathways.
2.Prevalence and Projections of Dementia in Ireland, 2011 – 46 by M Pierce genio.ie
3.Mendes, T., Ginó, S., Ribeiro, F., Guerreiro, M., Sousa, G.D., Ritchie, K. and de Mendonça, A., 2008. Memory complaints in healthy young and elderly adults: reliability of memory reporting. Aging and Mental Health, 12(2), pp.177-182.
4.A Guide to Memory Clinics in Ireland: dementia.ie