Young Onset Dementia: Not the same as later onset dementia. Highlighting the differences in diagnosis, care, treatment, and models of care

Anita Goh, DPsych¹³⁵, Monica Cations, PhD²⁵, Dennis Velakoulis, MD, PhD³⁵, Raymond Koopmans, MD, PhD^{4, 6*}

¹National Ageing Research Institute, Victoria, Australia
²Flinders University, South Australia
³The University of Melbourne/Melbourne Health, Victoria, Australia
⁴Department of Primary and Community Care: of the Radboud University Medical Center, Nijmegen, The Netherlands
⁵Australian National Special Interest Group in Young Onset Dementia
⁶ Joachim en Anna, center for specialized geriatric care, Nijmegen, the Netherlands
*Previous co-guest editor of the IPG special issue on YOD.

Young onset dementia (YOD) refers to a dementia where symptom onset occurs when the patient is less than 65 years of age. YOD is far less common than late-onset dementia (occurring when patients are over 65 years old) and often more challenging to diagnose due to its heterogeneous presentation (Koedam et al., 2009). The rising prevalence of dementia includes an increase of people with YOD (Hendriks et al., 2021), and YOD is known to have different psychosocial, medical, and policy implications than the more common later onset dementias.

In the Oceanic context, a recent invited editorial led by proposed editors Goh, Cations and Velakoulis highlighted the importance of addressing the specific issues in the YOD population (Cations, Loi, Draper, Swaffer, Velakoulis & Goh, 2021) and outlined pressing priorities for research, policy, service and advocacy with significant potential to improve outcomes for people with YOD and their care partners and families. In Norway, the Netherlands, Germany, Belgium and the UK, several studies are ongoing or completed in the field of people with YOD. In these studies, several topics are addressed, including epidemiology, challenging behavior, service provision and palliative care.

The last *International Psychogeriatrics* special issue on YOD was published in 2014, with four review articles, 12 research articles, one case study, one commentary, and on letter, edited by proposed editor Koopmans and his colleague Rosness (2014). This proposed YOD special issue will update the literature on YOD-related issues in psychogeriatrics. The field has advanced rapidly in the past seven years, including exciting developments in diverse fields such as basic research, psychosocial research, health economics, biomarker research, cognitive science, imaging research, clinical trials, services research, and implementation of policy (e.g. Graff-Radford et al., 2021; Hendriks et al., 2021; Nagaendran et al., 2015; Rodda & Carter, 2016).

We believe that there is a need for an updated international perspective, as YOD researchers are worldwide and this special issue is an opportunity to bring them together and offer different perspectives. The proposed *International Psychogeriatrics* special issue will help develop and advance existing knowledge regarding YOD, a field people interested in and working in psychogeriatrics and mental health should know more about (and have indicated to the proposed editors that they want to know more), and which will have international impact on clinical practice, training, research, and policy. Clinicians will benefit from the papers within the special issue regarding diagnosis and care for people with YOD, as little currently exists.

We will encourage submission of timely manuscripts and are interested in all methodologies relating to YOD, including manuscripts written in the context of the ongoing pandemic as well as in other contexts. We will also encourage contributions from consumer and community representatives. We will only publish papers that are of the highest quality, and will only accept data-based papers or systematic reviews. Case reports, commentaries, editorials, and letters will not be accepted. After articles are accepted, the editors will invite commentaries on those papers. Thus, we expect that several submissions would be rejected.

Proposed Timeline

Acceptance of proposal for special issue	October 2021
Dissemination of call for abstracts	November 2021
Abstract- 500 words - due	By Feb 2022
Selected abstracts are invited to submit full papers	By end Feb 2022
Invited papers are due	By 1st of June 2022
Invited papers are reviewed and selected papers become part of the	
special issue (an invitation to submit a paper does not mean an	
immediate or subsequent acceptance)	
Special issue is out	by March 2023

References

- Cations M, Loi SM, Draper B, Swaffer K, Velakoulis D, & Goh AM;. A call to action for the improved identification, diagnosis, treatment and care of people with young onset dementia. Aust N Z J Psychiatry. 2021 Sep;55(9):837-840. doi: 10.1177/00048674211037542. Epub 2021 Aug 12. PMID: 34382425.
- Graff-Radford J, Yong KXX, Apostolova LG, Bouwman FH, Carrillo M, Dickerson BC, Rabinovici GD, Schott JM, Jones DT, Murray ME. New insights into atypical Alzheimer's disease in the era of biomarkers. Lancet Neurol. 2021 Mar;20(3):222-234. doi: 10.1016/S1474-4422(20)30440-3. PMID: 33609479; PMCID: PMC8056394.
- Hendriks S, Peetoom K, Bakker C, van der Flier WM, Papma JM, Koopmans R, et al. Global Prevalence of Young-Onset Dementia: A Systematic Review and Meta-analysis. JAMA Neurology [Internet]. 2021 Jul 19 [cited 2021 Jul 24]; Available from: <u>https://doi.org/10.1001/jamaneurol.2021.2161</u>
- 4. International Psychogeriatrics , Volume 26 , Special Issue 12: young onset dementia , December 2014
- 5. Koedam EL, Lauffer V, van der Vlies AE, van der Flier WM, Scheltens P, Pijnenburg YA. Early-versus late-onset Alzheimer's disease: more than age alone. Journal of Alzheimer's Disease. 2009;19(4):1401–1408.
- 6. Koopmans, R., & Rosness, T. (2014). Young onset dementia what does the name imply? *International Psychogeriatrics*, *26*(12), 1931-1933. doi:10.1017/S1041610214001574
- 7. Nagaendran, K., Wang, V., Xuling, L., Nyu, M., Lim, L., Ng, A., ... Wee, H.W. (2015). Cost related to dementia in the young and the impact of aetiological subtype on cost. *Journal of Alzheimer's Disease*, *49*(2), 277–285.
- 8. Rodda, J., & Carter, J. (2016). A survey of UK services for younger people living with dementia. *International Journal of Geriatric Psychiatry*, *31*(8), 957–959. doi:10.1002/gps.4403