

## GUEST EDITORIAL

# Young onset dementia – what does the name imply?

People with dementia symptoms starting before the age of 65 years have special concerns and healthcare services should be particularly tailored to their specific needs. However, the literature and nomenclature concerning people with Young Onset Dementia (YOD) is unequivocal and consensus concerning the medical terms for when dementia affects younger individuals is warranted.

The rising prevalence of dementia includes an increase of people with YOD, and furthermore YOD is being steadily recognized as an important psychosocial and medical health problem with specific-age-related adverse consequences for both these younger persons and their families (Fadil *et al.*, 2009). However, many countries lack specific plans in their dementia strategies and do not offer any specific form of services or support for this group of individuals (Svanberg *et al.*, 2011; Kuruppu *et al.*, 2013). Therefore, the International Psychogeriatric Association (IPA) established a taskforce on YOD. The IPA taskforce on YOD has three objectives: (1) Establish a network of professionals and researchers that are involved in the care and needs of people with YOD; (2) Exchange ideas between different countries in order to improve care for people with YOD on a global scale; and (3) Set up international research projects within the field of YOD.

Since its formation, our taskforce has organized meetings, symposia, and workshops in Montreal, Santiago de Compostela, The Hague, Cairns, and Seoul. During The Hague meeting, several taskforce members visited the Florence Center for specialized care for people with YOD. This center's goal is to offer best possible care for people with YOD in the Netherlands (Bakker *et al.*, 2013; Millenaar *et al.*, 2013; Koopmans *et al.*, 2014). Countries should plan to adopt similar strategies of special care for people with YOD. France has for instance specific measures for people with YOD in their National Dementia Strategy as well as Norway. Our taskforce has encouraged a global act to address the need for services and programs/guidelines specifically targeted at people with YOD and their families (van Vliet *et al.*, 2010). Since research in this particular field of dementia is scarce, setting up international research projects is highly prioritized. The idea of composing a special issue on YOD was raised during The

Hague meeting in 2011, and the current issue consists partially of papers that have been presented during the symposia and workshop-meetings of our taskforce. Initially, the IPA taskforce was named the Early Onset Dementia (EOD) taskforce, however, during The Hague meeting the members of our taskforce decided upon changing the name into the YOD taskforce. In 2012, the IPA decided to change the name finally into Shared Interest Forums (SIF).

Agreeing upon the nomenclature of dementia with an onset before the age of 65 years is a matter of debate in the literature (Kelley *et al.*, 2008; Rossor *et al.*, 2010). Two main points are indispensable concerning younger persons with dementia. First, it is difficult to distinguish between two forms of dementia solely by age of onset, since elderly people with dementia differ in more aspects from younger people than simply in age (Koedam *et al.*, 2010). Genetics, hereditary patterns, pathophysiological mechanisms, heterogeneous etiology, course of illness, neurological and behavioral symptoms, pharmacological treatment, and carer support are all important YOD topics and several of them are well elucidated by different papers in this special issue. A recent Swedish study showed the importance of both cardiovascular and cognitive fitness to begin at age 18, in preventing YOD and pointing at a variety of etiological aspects in YOD (Nyberg *et al.*, 2014). The second point is how to answer the question: when in fact should a person with dementia be considered young? This salient point depends on to whom the individual is compared to. A 64-year-old person with dementia is not viewed as young compared to a 44-year-old with dementia, even though they both have been diagnosed with the same label of YOD. For centuries, medical terminology has posited the possibility to interpret the same clinical-debilitating condition differently and dementia is no exception. Nosology has still a way to go to define dementia starting before the age of 65 years more coherently (Masellis *et al.*, 2013).

Two comprehensive terms are commonly used in literature: *early onset dementia (EOD)* and *young onset dementia (YOD)*. These have themselves generated others to introduce terms like early onset Alzheimer's disease (EOAD) and young onset

Alzheimer's disease (YOAD), while some still use presenile dementia (Vieira *et al.*, 2013). Should we consider these individuals to be young and infer that the nomenclature YOD is most accurate? Or are they only *younger* than the average and more typical person with dementia? In Australia, they prefer using *younger onset dementia*, to express that these individuals are younger than those in general with dementia. Is this a more advantageous term? Confusion will nonetheless remain, since some studies use YOD to be appropriate only when it includes persons between the ages of 17 and 45 (Kelley *et al.*, 2008). The other option in terminology is to continue with the most frequently used term, EOD, which has a benefit in being contrasted by the term late onset dementia (LOD). However, some authors denote EOD to express that dementia is at an *early* stage and not pertaining to the age of onset *per se*, since it then also applies to elderly with dementia that started after the age of 65 years.

Studies have scrutinized the literature and documented distinct differences in traits between younger and older persons with dementia in several areas such as medical treatment, physical activity, functional level, activities of daily living, comorbidity, risk profiles, and caregiver distress (Werner *et al.*, 2009). However, the cut-off of 65 years is arbitrary and there is still no consensus on if a *diagnosis* of dementia has to be made before the age of 65 years or if it is sufficient that the first symptoms are detected before the age of 65 years? The term agreed upon by the IPA's SIF is young onset dementia. Using terms interchangeably adds to further dubiety and especially in areas of research, where concise operational definitions for disease entities are warranted in order to be able to compare international studies.

Our SIF on YOD wants to establish different partial goals in reaching our overall aim that will cohere well with the new strategic plan of the IPA, in increasing the number of meetings with one bi-annual meeting specifically focused on unique aspects of research. During the Seoul meeting, our SIF suggested to organize the first research-focused meeting on YOD. One of the major parts of this future meeting is to establish a consensus about the nomenclature as discussed in this guest editorial and further promote an international research agenda. As a teaser and research platform to build further upon in the upcoming meeting, this issue provides an overview of important topics including unmet needs of carers, different clinical approaches to YOD diagnoses, needs of children with YOD parents, and medical treatment of behavioral symptoms of YOD patients.

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## Conflict of interest

None.

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