

**Results:** Respondents described similar contexts for discussions about euthanasia: the topic arose at several key moments, usually with informal caregivers, and was motivated by patients considering the impact of disease progression both for themselves, thereby mainly wanting to avoid decline and maintain dignity, and their loved ones. Family caregivers paid considerable attention to the legality of euthanasia in dementia, specifically with regard to cognitive capacity, and elaborated on the difficulties and emotional impact of discussing euthanasia.

**Conclusions:** Considerations of people with young-onset dementia towards euthanasia appeared rooted in personal unbearable suffering and in expected interpersonal and societal consequences of their condition. Negative social framing of young-onset dementia might contribute to the livelihood of euthanasia in respondents' thoughts. The incorporation of euthanasia as a legal end-of-life option was mirrored in its incorporation in patients' and family caregivers' thought framework.

### **Perspectives of people with young-onset dementia on future quality of life: a qualitative interview study with implications for advance care planning**

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**Introduction:** Advance care planning (ACP), one of the key domains of palliative care, enables individuals to define and discuss goals and preferences for future treatment and care with family and healthcare professionals. By exploring the views of people with dementia on quality of life now and in the future, including the end of life, care provisions can be tailored to their values. The perspectives of people with young-onset dementia (YOD), with a symptom onset before the age of 65, may differ from those of older people with dementia given the different life phase and family context. Qualitative research methods can be used to elicit the attitudes and beliefs to generate insight into their perspectives.

**Methods:** Qualitative study, as part of the Care4Youngdem-study, using semi-structured interviews with a criterion-based purposive sample of community-dwelling people with YOD (n=10) and their (family) caregivers in the Netherlands. We adapted the interview guide based on discussion of the transcripts. Double coding of three interviews resulted in a codebook. The codes were subsequently analysed through thematic analysis.

**Results:** Interviews took place between December 2019 and February 2022. The most prevalent dementia subtype was Alzheimer's (n=7). Four overarching themes, based on 21 categories, were derived from the interviews: (1) connectedness with others, (2) sense of dignity, (3) acceptance versus no acceptance of the impact of dementia, (4) concerning oneself with the future versus not wishing to concern oneself with the future. Connectedness with others and a sense of dignity were deemed prerequisites for (future) quality of life but were affected by YOD. These themes overlapped in terms of axial codes. Ambiguities were seen in the attitude towards the impact of YOD and the preparation for the future. The degree of acceptance of YOD affected the orientation towards the future.

**Discussion:** Family and professional caregivers should discuss with people with YOD how to maintain connectedness with others and a sense of dignity. Opposite ways of coping with the present and future were found. Professional caregivers should take personal coping styles into account when starting ACP conversations.

### **Meeting IPA Shared Interest Forum on Young-onset Dementia**

Chair: Raymond Koopmans

With the rising prevalence of dementia, numbers of people with Young Onset Dementia will probably increase too. Young onset dementia is increasingly being recognized as an important psychosocial and medical health problem with serious consequences for both patients and their families. In several countries it is acknowledged that this group of people, in which dementia started before the age of 65 years, has special needs and therefore a need for support and health care services that are particularly designed to fit those needs. However, the number of these special health care services is scarce.

#### **Main Objectives of the Young Onset Dementia Shared Interest Forum:**

- Establishing a network of professionals and researchers that are involved in the care and research of people with Young Onset Dementia
- Exchanging ideas between countries to improve care for people with Young Onset Dementia
- Establish international research projects.

During the meeting we will explore opportunities for international collaboration in new research projects.

## **Keynote Lecture: Emerging Concepts in Combating Ageism, Protecting and Promoting Human Rights and Mental Health of Older Persons**

*Amal Abou Rafeh and Claudia Mahler*

### **Plenary Sessions**

#### **Plenary Session 1 : Healthy Ageing and the role of physical and social environments**

*John Beard*

Overview: The UN Decade of Healthy Ageing aims to foster the ability of people in the second half of life to be and to do the things they value. But, since older populations are extremely heterogenous, action cannot be generic. In 2015, WHO developed a life course approach that is tailored around the intrinsic capacity of the individual (including their cognitive and psychological capacity). This presentation will explore how this framework can help identify opportunities to foster healthy ageing through strategies to retain the highest level of capacity possible; break down ageist barriers; build environments that compensate for losses of capacity; and enable people to maintain lives of meaning and dignity despite significant losses.

#### **Plenary Session 2: Late onset psychosis / schizophrenia**

*Manabu Ikeda and Dilip Jeste*

Overview: This presentation will focus on late-onset schizophrenia (LOS) as well as ageing of persons with early-onset schizophrenia (EOS). 20% of middle-aged and older patients with schizophrenia have onset of illness after age 40. LOS is characterized by female preponderance, better premorbid functioning, fewer positive symptoms, and less cognitive impairment than EOS. EOS presents a paradox of aging – i.e., there is accelerated physical aging with multimorbidity and elevated mortality, while the mental well-being tends to improve with age. Adverse social determinants of health such as childhood traumas, social isolation, discrimination, and food insecurity worsen health. On the other hand, family and social support and access to necessary healthcare enhance the likelihood of sustained remission and recovery.