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Editorial

Palliative Care Needs in Young-Onset Dementia: A Commentary



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Although dementia is typically associated with older age, it is estimated that worldwide each year 370,000 people aged <65 years develop dementia.¹ Dementia is classified as "young-onset" (YOD) when first symptoms manifest before the age of 65 years.² Dementia is a progressive disease that results in increasing dependency and ultimately death. In 2015, an editorial by Koopmans et al concluded that research on palliative care in people with YOD is scarce.³ This editorial presented some hypotheses regarding differences between late- and young-onset dementia regarding survival rates, comorbidity, process of advance care planning (ACP), and pharmacotherapy of neuropsychiatric symptoms. Since that editorial, there has been a growing awareness of the need for more research on this topic. Recently, a review on palliative care needs in YOD was published in this journal.⁴ However, the search strategy used in that review was limited to the period up to 2022 in only the PubMed database. This commentary offers additional knowledge from research about palliative care in people with YOD complementary to the review by Dang et al.⁴

The palliative care needs of an individual relates to their survival time, burden of comorbidities, advance care planning, and pharmacotherapy. First, the survival time from diagnosis and from the first onset of symptoms will be discussed. The survival time in YOD differs among various cohorts (Table 1). Also, there are differences in survival time between subtypes of dementia.⁵⁻⁹ Notably, the survival time from diagnosis differs by more than 5 years from the survival time from the first onset of symptoms in YOD. In contrast, in older people with dementia, the survival time from diagnosis (5.4 years) differs only 1 year with the survival from onset of symptoms (6.3 years).^{6,8} On the other hand, the survival times from diagnosis in YOD are longer than those for late-onset dementia (LOD).^{6,7} People with YOD lost on average 60% to 94% of their life expectancy.⁵ The loss of remaining life expectancy in people with YOD is more than for people with LOD,

from 9.6 to 19.4 years and 1.3 to 9.2 years, respectively.⁵ There are differences in the expected loss of life-years between male and female: 11 years for males and 15 years for females.⁶ So, the remaining life expectancy of people with YOD, after diagnosis, is reduced at 52% in male and 61% in female.⁷ In addition, we agree with Dang et al that further research regarding a possibly more rapid decline in YOD is needed.⁴ In the NeedYD study including community-dwelling people with YOD, the overall cognitive decline over 2 years was 1.6 points on the MMSE, participants with AD showed the greatest decline of 2.3 points. However, the cognitive decline appears to be less progressive than that of older people with AD, which challenges the notion of a more rapid decline in YOD.¹⁰ Moreover, patients with YOD are cared for at home for a longer period than patients with LOD. The NeedYD study found that the time from symptom onset to institutionalization for YOD was almost 9 years compared with 4 years for LOD.¹¹ A recent review showed also that the time to nursing home admission in patients of older age at diagnosis was significantly shorter. In people with dementia aged 70 years, the average time to admission in a nursing home is 5 years. By contrast, in people with dementia aged 85 years, the average time to admission is 1 year.¹² The most common causes of death in people with YOD is a complication of advanced dementia rather than a comorbid illness, including aspiration pneumonia, nervous system disease, diseases of the circulatory system, cachexia and dehydration, and gastrointestinal disease.^{9,13} Robmeier et al found no clear differences in the causes of death between LOD and YOD in a sample of deceased persons with advanced YOD and LOD.¹⁴ However, there are significant differences between people with YOD and LOD in terms of comorbidities. People with YOD exhibited a lower prevalence of cardiovascular, respiratory, and musculoskeletal comorbidities and a higher prevalence of depressive comorbidities compared with LOD.^{15,16}

ACP appears to be suboptimal in people with YOD, whereas there has been a growing number of studies on ACP in YOD over the past years. A retrospective chart review in Ireland found that 11% of the people with YOD had documented any form of ACP, and 27% had an advance directive.¹³ According to family caregivers of Flemish people with YOD, 27% had completed some advance directives, 40% did not document any wishes, and 20% indicated that they were unaware if there were any documented wishes.^{17,18} It is likely that more older people with dementia had an ACP documentation. In an Australian study in 2019, 60% of older people with dementia and aged 65 years or

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Table 1
Survival Time

	Survival Time From Diagnosis to Death, y, Mean or Median (95% CI)			Survival Time From Onset of Symptoms to Death, y, Mean or Median (95% CI)		
	Brodaty et al ⁵ (2012)	Rhodijs-Meester et al ^{6,*} (2019)	Gerritsen et al ⁷ (2019)	Gerritsen et al ⁷ (2019)	Loi et al ^{8,*} (2022)	van Engelen et al ⁹ (2020)
Total sample	7.9 [†]	6.9 (6.5-7.2)	10 (9.2-10.8)	17.4 (15.4-18.6)	12.7 (11.2-13.7)	11.7 (2.9-20.5)
AD		7.0 (6.6-7.6)	9.3 (8.3-10.3)	15.6 (13.4-17.8)	11.2 (10-12.8)	11.6 (1.0-22.2)
VaD			11.8 (9.9-13.8)	22.5 (12.7-27.3)	12.3 (8.9-16.2)	
FTD	1.3 [†]	7.0 (6.2-7.9)	10 (8.4-11.7)	16.4 (14.3-18.4)	10.7 (8.2-14.3)	12 (3.2-20.8)
LBD		5.7 (4.6-6.7)				

AD, Alzheimer disease; DLB, lewy body dementia; FTD, frontotemporal dementia; VaD, vascular dementia.

*In these studies, the median (95% CI) is shown.

[†]95% CI is not known.

older had a form of ACP documentation.¹⁹ However, the most recent research from the Netherlands found that 98.9% of YOD nursing home residents had a global care goal.²⁰ Maters et al concluded that global care goals particularly focused on comfort (73.9%) and improving function (14.1%), but hardly on life prolongation (8.7%).²⁰ There was a higher number of do-not-treat orders than the do-treat orders and were most common with regard to resuscitations and admission to intensive care unit. A recent focus group with physicians from Belgium found that end-of-life care in YOD differs in certain aspects from that of LOD, for example, the difference in life context. People with YOD have younger children and spouses, which makes questions about end-of-life wishes more salient. Compared with LOD, people with YOD tend to be more articulate and assertive, have more control needs, have a diminished acceptance of their diagnosis, have increased grief, and have family conflict over financial matters.²¹ So, the young age of people with dementia influences the content of the ACP discussions.²¹ In addition, patients and caregivers are not only focused on the medical aspects of ACP but also on nonmedical elements of planning for the future, such as financial planning.¹⁸ Also, the topic of euthanasia can occur in ACP discussions, as described in a qualitative study from Belgium.²² Both the physicians and the patients and caregivers believe that the general practitioner plays a key role in ACP.^{17,18,21} The timing of ACP should be timely but allow the patient time to process the diagnosis.¹⁶ Therefore, it is desirable to initiate ACP discussions at an early stage, preferably before admission to a nursing home.²⁰

At this moment, there are still no studies available about the appropriate use of psychotropic drugs in people with YOD. In a recent Dutch cohort, 72% to 87% of people with YOD residing in a nursing home received at least 1 psychotropic drug, of which 21.3% to 50.7% were antipsychotics and 14.4% to 49.3% antidepressants. At least 47% of these residents used 2 or more psychotropic drugs.^{20,23,24} The most prevalent combination of prescribed drugs was an antipsychotic with an antidepressant or an anxiolytic drug.²³ Notably, the use of antipsychotic is lower (10%) in people with YOD living at home.²⁴ There was no association between the specific type of dementia and the use of psychotropic drugs.²⁴ A systematic review about the effectiveness of pharmacologic interventions for symptoms of behavioral variant frontotemporal dementia (bvFTD) showed that different psychotropic drugs reduced the symptoms of bvFTD in young and old people, including citalopram, rivastigmine, paroxetine, and trazodone.²⁵ A study by Appelhof et al showed that the use of psychotropic drugs was higher in YOD residents (77%) compared with LOD residents (55%).²⁶ Pharmacologic studies with a specific focus on young people with dementia are lacking. There are no studies available about the optimal doses of pharmacotherapy.

Further research should focus on cognitive decline in YOD, symptom burden at the end of life, the appropriateness of psychotropic

drug use, and the optimal doses of pharmacotherapy (or the potential for reducing its use). We concur with the recommendations for further research of Dang et al regarding postdiagnostic care, specifically the need for early referral to relevant support services.⁴ Additionally, the ACP process remains unclear. There is a lack of clarity regarding the individual responsible for initiating ACP and the optimal timing for doing so. Further research is also required to determine the content of the ACP and which topics should be discussed. Additionally, the views of the children of people with YOD on ACP, and the prevalence of euthanasia in YOD, must be investigated.

Disclosure

The authors declare no conflicts of interest.

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