International Psychogeriatrics xxx (xxxx) xxx

Contents lists available at ScienceDirect

International Psychogeriatrics

journal homepage: www.sciencedirect.com/journal/inpsyc

Original Research Article

Survival and determinants of mortality in nursing home residents with young onset dementia

Jasper Maters, MD[a,b,*], Jenny T. van der Steen, MSc, PhD, FGSA[a,b,c,d], Marjolein E. de Vugt MSc, PhD[e], Ans Mulders, MD[f], Christian Bakker, MSc, PhD[a,b,g], Raymond T.C.M. Koopmans, MD, PhD[a,b]

[a] Department of Primary and Community Care, Radboud University Medical Center, Nijmegen, the Netherlands
[b] Radboudumc Alzheimer Center, Nijmegen, the Netherlands
[c] Department of Public Health and Primary Care, University Medical Center Leiden, Leiden, the Netherlands
[d] Cicely Saunders Institute, King's College London, London, United Kingdom
[e] Alzheimer Center Limburg, Mental Health and Neuroscience research institute, Maastricht University Medical Center, Maastricht, the Netherlands
[f] Thebe, Center for Geriatric Care, Breda, the Netherlands
[g] Groenhuysen, Center for Geriatric Care, Roosendaal, the Netherlands

ARTICLE INFO

Keywords:
Young-onset dementia
Dementia
Nursing home
Long-term care
And mortality

ABSTRACT

Objectives: People with young-onset dementia (YOD), defined as symptom onset before the age of 65, have mortality rates five to eight times higher than those of the general population of similar age. However, survival studies focused on individuals living in the community rather than those residing in nursing homes. This study aimed to estimate survival rates, its determinants, and causes of death in nursing home residents with YOD.
Design: Survival data from the BEYOnD (2005–2018) and Care4Youngdem (2016–2021) cohort studies.
Setting: YOD special care units of 20 nursing homes in the Netherlands.
Participants: Nursing home residents with YOD (N = 385).
Methods: Kaplan-Meier estimates were used to determine survival times. Cox regression analysis examined factors associated with mortality, including age, sex, dementia type, and cardiovascular and pulmonary diseases. Hazard ratios were pooled using a random-effects meta-analysis.
Results: Median survival after diagnosis was 8.9 years (95 % CI 7.8–10.1) in BEYOnD and 7.9 years (95 % CI 6.9–9.0) in Care4Youngdem. Median survival after admission was 6.3 (95 % CI 5.3–7.2) and 5.0 (95 % CI 4.4–5.6) years, respectively. In the pooled model, higher age at diagnosis (HR 1.06 per year increment) and male sex (HR 1.36) were significantly associated with higher mortality; dementia type and comorbidities were not. Cachexia or dehydration was the most frequent cause of death (35.3 %).
Conclusions and Implications: Nursing home residents with YOD have long survival times, in particular women and those diagnosed at younger ages. Our results highlight important considerations for prognostication and organizing long-term care.
Trial registration: NL-OMON23226 (Registry: OMON).

Introduction

Dementia represents a growing health concern, with rising mortality rates as the world's population ages [9]. Globally, the number of dementia-related deaths is projected to increase to around 5 million by the year 2050 [29]. On an individual level, survival time in dementia varies considerably and is influenced by factors such as age, sex, type of dementia, and comorbidities [17,4,40,42].

Although dementia is typically associated with older age, it can also occur in younger individuals. If symptoms start before the age of 65, it is defined as young-onset dementia (YOD) [43]. YOD is caused by a wide range of etiologies, with Alzheimer's disease, vascular dementia,

* Correspondence to: Department of Primary and Community Care, Radboudumc, Geert Grooteplein 21, Nijmegen 6525 EZ, the Netherlands.
E-mail address: jasper.maters@radboudumc.nl (J. Maters).

https://doi.org/10.1016/j.inpsyc.2025.100175
Received 21 October 2025; Received in revised form 25 November 2025; Accepted 24 December 2025

and frontotemporal dementia being the most common [18,35]. A systematic review and meta-analysis found an age-standardized prevalence of 119.0 per 100,000 population in the age range of 30–64 years, corresponding to an estimated 3.9 million people aged 30–64 years worldwide living with YOD [18]. As a result, YOD has considerable social and economic impact, including premature work cessation, and extended informal and formal care needs [24].

Compared to those with late-onset dementia (LOD), people with YOD lose a significantly larger portion of their remaining life expectancy [4]. Overall, people with YOD have mortality rates five to eight times higher than the general population of similar age [31]. Median survival times after diagnosis range from 3.0 to 9.3 years [16,22,4]. Cohort studies in people with YOD show shorter survival with older age. Sex, dementia type, and comorbidities are not consistently associated [15,30,31,8]. The increased mortality rates can be attributed to dementia itself as cause of death, with other common causes being respiratory and cardiovascular diseases [25,41].

Previous studies on YOD survival have focused on individuals living in the community. However, people with YOD also reside in nursing homes. Comparisons between community-dwelling individuals and nursing home residents with YOD suggest that the latter group has more advanced dementia, a higher prevalence of neuropsychiatric symptoms, and more do-not-treat orders [33,34,48]. These factors are relevant to mortality outcomes [3,42]. Moreover, findings from studies conducted in community settings may not generalize to those admitted to a nursing home, as these individuals have survived a certain disease duration prior to admission. This makes a new estimation of survival after admission particularly relevant. Nevertheless, to our knowledge, no studies have specifically examined survival in nursing home populations with YOD.

Knowledge on survival in nursing home residents and its determinants could be helpful for healthcare professionals. Prognostication, a domain of palliative care, may facilitate discussions on advance care planning [10,45]. Therefore, the aim of this study was to estimate survival rates, its determinants, and causes of death in a sample of nursing home residents with YOD.

Methods

Study design

We used the data from the only two available observational prospective cohort studies in nursing home residents with YOD: the BEYOnD-study and the Care4Youngdem-study [33,34]. Residents lived in specialized units of 20 nursing homes across the Netherlands, with four nursing homes participating in both studies. The special YOD care units were affiliated with the Young-Onset Dementia Knowledge Center [1] offering residential care guided by a quality hallmark. Although the units varied in organizational characteristics and specific admission criteria, they typically admitted residents diagnosed with YOD and aimed to provide age-appropriate care tailored to the specific needs of younger people with dementia [50].

Both studies included residents with a diagnosis of dementia with first symptom onset before the age of 65. Informed consent was provided by the legal representative. In BEYOnD, the diagnosis in the medical records was verified by one of the researchers (AM) according to DSM-IV-TR criteria, while in Care4Youngdem, the dementia type and date of diagnosis was reported by the participating physician. An additional criterion for BEYOnD was a minimum residency of four weeks in the nursing home. Residents with alcohol-related dementia were excluded because, in the Netherlands, they typically follow a different trajectory: they are admitted to a Korsakoff clinic for diagnostic work-up and are cared for in specialized Korsakoff long-term care units rather than YOD care units [14,26].

In BEYOnD, inclusion took place from December 23, 2005 to October 28, 2008, and was limited to a single continuous period of up to three months per care unit, awaiting informed consent. In contrast, recruitment in Care4Youngdem was ongoing throughout the inclusion period (October 9, 2016 to February 22, 2020), allowing for the continuous inclusion of newly admitted residents.

Data collection and categorization

Baseline data were collected from medical records (BEYOnD) and through questionnaires completed by physicians (Care4Youngdem). Demographic data included age and sex. If the exact day or month of diagnosis was unknown, we used the midpoint of the respective month or year.

We categorized the type of dementia as Alzheimer's dementia (AD), vascular dementia (VaD), including mixed dementia of AD and VaD, frontotemporal dementia (FTD), and 'other type', which included dementia not otherwise specified, other mixed dementia, and miscellaneous types. Dementia severity was assessed with the Global Deterioration Scale (GDS), a 7-point scale ranging from normal cognition (stage 1) to very severe cognitive decline (stage 7) [36]. GDS scores were categorized as normal to mild (GDS 1 – 4), moderate (GDS 5), severe (GDS 6), and very severe (GDS 7). We classified comorbid diseases using the International Classification of Diseases, 10th Revision (ICD-10) into cardiovascular disorders, including cerebrovascular disease and diabetes mellitus (I10-I79 and E08-E13), and pulmonary diseases (J30-J84). These categories were chosen due to their known associations with frequent causes of death in YOD [25,41].

Follow-up data included resident status (alive, relocated or dead), and date of death or relocation. For BEYOnD, care units were contacted on April 1, 2014 and again on December 31, 2018 to ascertain resident status. In Care4Youngdem, nursing staff members were asked to actively report resident deaths, with reminders sent every three months until December 31, 2021. Residents were censored if they were still alive at the end of follow-up or if they had relocated to a care unit that did not participate in the study.

The cause of death, as registered by the attending physician was used. For the analysis, we categorized the immediate causes of death, as listed in Part 1a of the Dutch death certificate, according to the International Classification of Diseases and Related Health Problems (ICD-10) into dementia (F01-F03 and G30-G31), cachexia or dehydration (R64 or E86), acute respiratory disease (J00-J22), cardiovascular disease, other natural causes, and non-natural causes. Further, we examined the potential indirect role of dementia by reviewing whether it was reported as an underlying cause (Part 1b and 1c).

Statistical analysis

Survival times were analyzed separately across the datasets given differences in cohort characteristics, including follow-up periods and inclusion criteria. We performed Kaplan-Meier analyses to estimate mean and median survival times after diagnosis and after admission. Statistical differences between the cohorts were assessed with log-rank tests.

Additionally, we conducted a sensitivity analysis to account for potential length bias resulting from left truncation [52]. Specifically, we examined survival times for residents who were included within three months after admission, given the known elevated mortality risk following admission in older nursing home populations with dementia [46]. Their survival times were compared with those of residents included more than three months after admission.

Kaplan-Meier analyses including log-rank tests were also conducted to compare survival times after diagnosis based on age at diagnosis, which was stratified into three groups ($\leq$55, 55–60, and $\geq$60 years), sex, dementia type, and comorbidity. Further, we used multivariable Cox regression analysis, including age at diagnosis, sex, dementia type, and comorbidity (cardiovascular and pulmonary) as covariates, to assess their independent associations with survival after diagnosis in each cohort. The proportional hazards assumption was tested by examining

Table 1
Participant characteristics.

Variable	BEYOnD (N = 187)	Care4Youngdem (N = 198)
Male sex, % (N)	51.3 (96)	49.0 (97)
Mean age at diagnosis (SD)[a]	55.3 (7.5)	59.1 (6.3)
Mean age at admission (SD)[b]	57.8 (7.3)	61.7 (6.3)
Mean age at inclusion (SD)[c]	60.4 (7.2)	63.6 (5.9)
Mean age at death (SD)[d]	64.4 (6.4)	65.7 (6.3)
Severity of dementia at inclusion, % (N)[e]		
GDS ≤4 (up to mild)	14.7 (27)	11.2 (22)
GDS 5 (moderate)	20.7 (38)	24.5 (48)
GDS 6 (severe)	33.2 (61)	37.3 (73)
GDS 7 (very severe)	31.5 (58)	27.0 (53)
Type of dementia, % (N)[f]		
Alzheimer's dementia	38.5 (72)	45.4 (88)
Vascular dementia	16.0 (30)	14.9 (29)
Frontotemporal dementia	18.7 (35)	20.1 (39)
Other type[g]	26.7 (50)	19.1 (37)
Comorbid disease at inclusion, % **(N)**[h]		
Any comorbidity	70.1 (131)	84.2 (165)
Cardiovascular diseases	26.2 (49)	46.9 (92)
Pulmonary diseases	8.0 (15)	5.1 (10)

[a] N = 182 and N = 194
[b] N = 186 and N = 196
[c] N = 184 and N = 196
[d] N = 136 and N = 89
[e] N = 184 and N = 196
[f] N = 187 and N = 194
[g] Three most common causes for BEYOnD: Huntington's disease (N = 8), post-anoxic encephalopathy (N = 6), and Lewy Body dementia or Parkinson's disease dementia (N = 6); three most common causes for Care4Youngdem: Lewy body Dementia or Parkinson's disease dementia (N = 13), mixed dementia (N = 7), and dementia not otherwise specified (N = 3)
[h] N = 187 and N = 196

the parallelism of the log-log survival curve and by including a time-dependent covariate [27]. Finally, we performed a meta-analysis to pool hazard ratios (HR) from both cohorts. This approach allowed for interpretation of survival trends across cohorts. A random-effects model was used to account for heterogeneity between the studies [12].

Results with two sided p-values < 0.05 were considered statistically significant. Statistical analyses were performed in IBM SPSS Statistics 29, GraphPad Prism 10, and R version 4.1.3.

Ethical considerations

Both studies were reviewed and deemed exempt from the Medical Research Involving Human Subjects Act (WMO) by the designated HREC (CMO Regio Arnhem-Nijmegen). They were conducted in accordance with the principles of the Declaration of Helsinki and the Dutch Medical Treatment Contracts Act.

Results

Characteristics of study participants

A total of 187 residents from BEYOnD and 198 from Care4Youngdem were included (Table 1). The male-to-female ratio was close to 1:1 in both cohorts. Residents in BEYOnD were, on average, younger at diagnosis (55.3 years) and at admission (57.8 years) compared to those in Care4Youngdem (59.1 and 61.7 years, respectively). Alzheimer's dementia was the most common dementia type in both BEYOnD (38.4 %) and Care4Youngdem (45.4 %). Most residents had comorbidity, with a higher proportion in Care4Youngdem (84.2 %) than in BEYOnD (70.1 %).

Survival

During the follow-up period (Supplementary S1) of BEYOnD, 138 participants (73.8 %) died, while 49 participants (26.2 %) were censored, including nine who were confirmed to be alive on the end date. In Care4Youngdem, 117 participants (59.1 %) died, and data for the other 81 participants (40.9 %) were censored, with 62 known to be alive at the end of follow-up.

The median survival time from diagnosis was 8.9 years (95 % CI 7.8–10.1) for BEYOnD and 7.9 years (95 % CI 6.9–9.0) for Care4Youngdem (Table 2 and Fig. 1). When measured from admission, the median survival times were 6.3 years (95 % CI 5.3–7.2) and 5.0 years (95 % CI 4.4–5.6) in BEYOnD and Care4Youngdem, respectively. Survival times after both diagnosis ($P = 0.43$) and admission ($P = 0.12$) did not differ significantly between the two cohorts. Sensitivity analyses (Supplementary S2) showed significantly lower survival times for newly admitted residents compared to those included more than three months after admission in both BEYOnD (median 2.4 vs. 6.6 years, $P < 0.001$) and Care4Youngdem (median 3.1 vs. 5.5 years, $P < 0.001$), suggesting length-bias.

Determinants of survival

In both cohorts, those with the highest age at diagnosis had the shortest survival times (Supplementary S3). In Care4Youngdem, survival was significantly shorter for men than women (median 7.2 vs. 8.5 years, $P = 0.02$). Survival times in BEYOnD were similar (median 8.7 vs. 9.2 years, $P = 0.70$). Individuals with Alzheimer's dementia had the shortest median survival times in both cohorts (7.6 and 7.7 years). Residents in BEYOnD with cardiovascular disease had significantly shorter survival times compared to those without (median 6.8 vs. 9.5 years, $P = 0.03$). This finding was not observed in Care4Youngdem. The proportional hazards assumption was met for all determinants except dementia type, as the hazard ratio was not constant over time, with variations across dementia types.

Age at diagnosis (HR 1.063; 95 % CI 1.041–1.086) and male sex (HR 1.37; 95 % CI 1.04–1.80) were associated with increased mortality after pooling the Cox proportional hazards models from the two cohorts (Supplementary S4). In Care4Youngdem, vascular dementia (HR 0.68; 95 % CI 0.36–1.31) and frontotemporal dementia (HR 0.51; 95 % CI

Table 2
Median and mean survival times of the two cohorts.

Survival time in years	BEYOnD	Care4Youngdem	P-value*
After diagnosis (N = 181 and N = 194)			0.43
Median (95 % CI)	8.9 (7.8 – 10.1)	7.9 (6.9 – 9.0)	
Mean (95 % CI)	10.1 (0.5)	9.9 (0.7)	
After admission (N = 185 and N = 196)			0.12
Median (95 % CI)	6.3 (5.3 – 7.2)	5.0 (4.4 – 5.6)	
Mean (SE)	8.0 (0.5)	6.4 (0.4)	

* Differences in survival times between the cohorts were assessed using the log-rank test with p-values < 0.05 indicating a significant difference

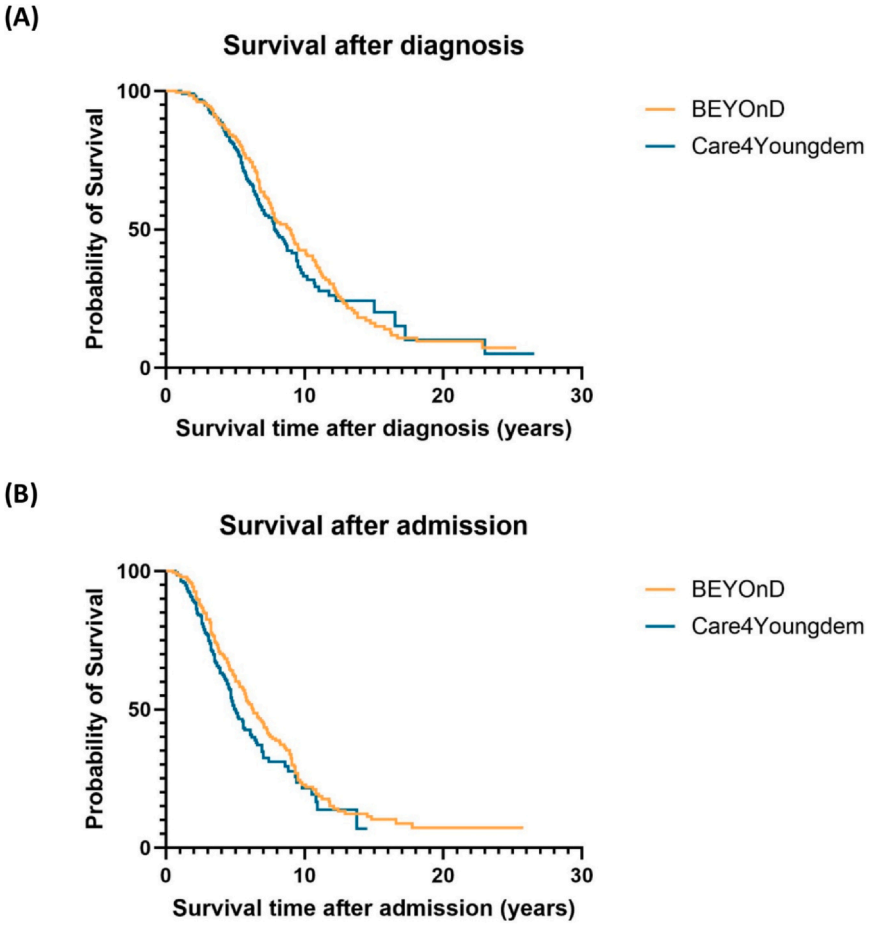

Fig. 1. Kaplan Meier estimates for survival times.

Table 3
Pooled multivariable Cox proportional hazard model for survival after diagnosis.

Determinant	Hazard ratio (95 % CI)	P-value*
Age at diagnosis, increase per year	1.063 (1.041 – 1.086)	< 0.001
Male sex	1.37 (1.04 – 1.80)	0.03
Dementia type		
Alzheimer's dementia (ref)	1	
Vascular dementia	0.90 (0.57 – 1.41)	0.63
Frontotemporal dementia	0.79 (0.39 – 1.62)	0.52
Other type	0.89 (0.50 – 1.57)	0.68
Comorbidity		
Cardiovascular diseases	1.13 (0.81 – 1.59)	0.47
Pulmonary diseases	1.02 (0.62 – 1.68)	0.95

*In the Cox proportional hazards model, p-values indicate whether the association between each variable and the hazard of death is statistically significant, with $p < 0.05$ considered significant

0.28–0.93) were associated with longer survival times (Table 3). However, no significant association with survival was found for dementia type or comorbid diseases in the pooled model.

Causes of death

The most common immediate cause of death (Table 4) was cachexia or dehydration (35.3 %) followed by respiratory infections (28.2 %). Cardiovascular disorders accounted for 9.1 % of cases. Dementia was cause of death in more than half of the cases; reported as either the immediate cause (8.1 %) or the underlying cause (49.6 %).

Table 4
Immediate causes of death (N = 220).

Cause of death	% (N)
Cachexia or dehydration	35.3 (78)
Respiratory infection	28.2 (62)
Cardiovascular disease	9.1 (20)
Dementia	8.1 (18)
Other causes, natural[a]	17.1 (38)
Other causes, non-natural	1.8 (4)

[a] Other causes include unspecified infection (N = 8); urinary tract infection (N = 5); non-infectious, acute abdomen (N = 5); infection other than urinary tract infection and respiratory infection (N = 4); mors subita (N = 3); respiratory failure, not related to infection (N = 3), dysphagia (N = 2), and miscellaneous (N = 8).

Discussion

This is the first study investigating survival, its determinants, and causes of death in nursing home residents with YOD. Median survival times after diagnosis in BEYOnD and Care4Youngdem were 8.9 and 7.9 years, respectively. Following admission, median survival times were 6.3 and 5.0 years, respectively. After pooling the cohorts, higher age and male sex were significantly associated with shorter survival, whereas dementia type and comorbid diseases were not. The most common primary cause of death was cachexia or dehydration, affecting more than a third of residents. Dementia itself was an underlying cause of death in almost half of all cases.

Residents in Care4Youngdem were on average older than in BEYOnD, which can explain the higher prevalence of comorbidities.

The proportion of other types of dementia, especially Huntington's disease and post-anoxic encephalopathy, was higher in BEYOnD, which may indicate that admission criteria differed between care units. Despite these differences, the BEYOnD cohort demonstrated similar survival times as the more recent Care4Youngdem cohort, indicating that YOD survival did not improve or deteriorate over time. This finding is in line with previous studies including people with YOD [37,4].

When comparing our findings with other YOD-studies, we report relatively long survival times after diagnosis. The median survival times in our studies exceed those of a systematic review (3.0–7.9 years) and a Dutch memory clinic cohort (6.9 years), with the NEEDYD-study being the exception, reporting longer survival (9.3 years) [16,37,4]. However, these studies followed individuals from earlier in the disease trajectory, presumably leading to less left-truncation. Further, our cohort exhibited distinct characteristics, including a high proportion of other types of dementia, a high prevalence of comorbid diseases, and residents in the BEYOnD cohort being diagnosed at a relatively young age [13,37,49,7].

Importantly, our survival times after admission may be up to twice as long as those observed in typical nursing home populations with dementia [23,51]. Further, our nursing home population with YOD is nearly 20 years younger and has a more balanced male-to-female ratio. These factors should be considered in long-term care planning.

When considering demographics, the association between advancing age and higher mortality aligns with previous research into YOD-populations [16,4,53]. This association remains significant in our multivariable analysis, independent of comorbidities. Consequently, the youngest residents are expected to live with dementia for the longest duration, experiencing an extended period of cognitive decline. This finding is particularly relevant for individuals with AD, as younger age at onset has also been associated with a more rapid annual cognitive decline [11,2,39]. Additionally, male sex emerged as a significant risk factor for mortality in the Care4Youngdem cohort and the pooled analysis. Previous findings on sex differences, primarily in community-dwelling YOD survival have been inconsistent [16,30,4]. Residents with YOD in nursing homes may exhibit distinct survival patterns compared to individuals in community settings. Similarly, male sex has been identified as a determinant of mortality in older nursing home populations with dementia, but not in a systematic review including community based cohorts [44,5].

Regarding dementia-related variables, only dementia type could be included in the Cox regression analysis. Differences in survival times were observed by dementia type, with the shortest survival times for individuals with AD. However, in the pooled model, we found no significant association with dementia type. Previous studies on YOD have reported the shortest survival in FTD [31] and in individuals with 'other types of dementia' [37]. In the latter study, this category included rarer dementia types and dementia of unspecified etiology, but did not include Lewy body dementia or Parkinson's disease dementia as in our cohort. Neither of these studies adjusted for age, sex, and comorbidity. The NEEDYD study, which accounted for these factors, found shorter survival in AD compared to VaD [16].

Beyond demographics and dementia type, we examined the role of comorbidity in YOD. In the pooled model, cardiovascular disease was not significantly associated with survival. Although cardiovascular comorbidity was prevalent, their contribution as a cause of death was relatively low compared to older nursing home populations with dementia [20]. Pulmonary disease also showed no association with survival in our analysis, even though respiratory infections were a common cause of death. Previous studies have been inconsistent regarding the role of comorbidity, some linking comorbidity, including cardiovascular diseases and COPD, to shorter survival in YOD, while other studies found no such association [16,40,53,8]. Notably, most previous studies assessed comorbidity at the time of diagnosis, whereas our data were collected at a different time point, without knowledge of the duration. Our findings show that the disease trajectory and mortality in our cohort are not significantly influenced by important comorbid diseases. This may be because individuals with YOD are less susceptible to developing fatal complications from these comorbid conditions given their age, as the impact of comorbidity tends to be more pronounced in older dementia populations [10,54,6,8].

Understanding the causes of death in YOD provides additional insights into survival patterns. In our sample, the percentage of cachexia or dehydration as primary cause of death was similar to percentages (35–38 %) found in older Dutch nursing homes populations, in which it was particularly common for those who survived to the final phase [20]; [28]. In case of YOD, high prevalence of swallowing problems has been reported in the final stage, which can contribute to this complication [28,38,47]. Studies from other countries have not specifically reported cachexia or dehydration, possibly due to differences in recording practices, with dementia itself often registered as the primary cause of death [31,41]. Whereas, in our study dementia was most frequently reported as underlying cause of death. We also found high prevalence of respiratory infections, consistent with data from YOD populations and older dementia populations [32,41]. Our results may reflect treatment practices, such as orders not to provide artificial feeding and hydration or not to use antibiotics in our population [33]. In conclusion, despite the relatively better life expectancy of residents with YOD compared to those with LOD, similar dementia-related complications affecting survival eventually occur [21].

Strength and Limitations

We included data from two different cohort studies, improving the external validity of our findings. The long follow-up period in the BEYOnD cohort resulted in relatively few censored cases. However, a limitation of our study lies in the inclusion of residents, who, on average, were admitted several years before study enrollment. This approach introduces length bias due to selective missing data for individuals who died shortly after admission, particularly in the BEYOnD cohort, which required a minimum of four weeks of residency as an inclusion criterion. However, sensitivity analyses allowed us to report additional results unaffected by length bias.

Second, due to the study design we lacked data at the time of diagnosis, limiting our ability to assess possibly relevant determinants of survival. Relatedly, we were unaware of how long the comorbidities had been present. This may matter for progressive conditions, where a longer disease history increases mortality risk. However, we expect this effect to be minor, as residents in our population more often died from dementia-related complications or intercurrent illnesses rather than from complications of the comorbidities themselves.

Third, our findings may be specific to special care units in the Netherlands. Cohort studies into regular nursing homes or in other countries may yield different survival outcomes, depending on factors such as admission criteria impacting resident characteristics at admission. In addition, palliative care practices which are common in Dutch nursing homes, focusing on symptom management rather than life prolongation, may impact outcomes [19]. Finally, the cause of death was based on clinical understanding of the patient's terminal trajectory and physical examination, rather than on pathological findings, as autopsies are rarely performed in the Netherlands. Consequently, some misclassification may have occurred.

Conclusions and Implications

Residents with YOD in special care units represent a distinct population with long survival times after admission, leading to increased demand for long-term care. Prognostication should primarily consider age and sex, given their association with mortality. Advance care planning must address the extended trajectory of dementia, which is minimally impacted by comorbidity, including its complications and intercurrent diseases such as respiratory infections.

Future research should aim to follow participants from moment of diagnosis, using an inception cohort design. Follow-up could then continue after admission to a nursing home. Studies should include determinants associated with mortality in LOD, such as dementia severity, functional status, and weight loss, while controlling for demographics. Longitudinal studies on dementia-related complications and intercurrent diseases could provide valuable insights into the disease trajectory for individuals with YOD. Finally, exploring the exact circumstances surrounding death, including treatment practices, would be valuable for better interpreting causes of death, particularly in cases of cachexia or dehydration.

Funding

The work was supported by ZonMw (project number 839120003).

CRediT authorship contribution statement

Jasper Maters: Writing – review & editing, Writing – original draft, Visualization, Methodology, Formal analysis, Conceptualization. **Van der Steen Jenny:** Writing – review & editing, Supervision, Project administration, Methodology, Funding acquisition, Conceptualization. **De Vugt Marjolein:** Writing – review & editing. **Ans Mulders:** Writing – review & editing, Methodology, Investigation, Formal analysis, Conceptualization. **Koopmans Raymond:** Writing – review & editing, Project administration, Methodology, Funding acquisition, Conceptualization. **Christian Bakker:** Writing – review & editing, Methodology, Funding acquisition, Conceptualization.

Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests:Jasper Maters reports that financial support was provided by Netherlands Organisation for Health Research and Development (ZonMw). The other authors, they declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgements

We would like to thank all the respondents and the participating nursing homes for their contributions, Brenda Pistorius for her help with the study design, Stijntje Bokdam for her support with the data collection, and Scott Maurits (IQ Health, Radboudumc) for his statistical guidance.

Declaration of interests

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.inpsyc.2025.100175.

References

[1] Bakker C, Verboom M, Koopmans R. Reimagining Postdiagnostic Care and Support in Young-Onset Dementia. J Am Med Dir Assoc 2022;23:261–5.
[2] Barnes J, Bartlett JW, Wolk DA, van der Flier WM, Frost C. Disease Course Varies According to Age and Symptom Length in Alzheimer's Disease. J Alzheimers Dis 2018;64:631–42.
[3] Bränsvik V, Granvik E, Minthon L, Nordström P, Nägga K. Mortality in patients with behavioural and psychological symptoms of dementia: a registry-based study. Aging Ment Health 2021;25:1101–9.
[4] Brodaty H, Seeher K, Gibson L. Dementia time to death: a systematic literature review on survival time and years of life lost in people with dementia. Int Psychogeriatr 2012;24:1034–45.
[5] Brück CC, et al. Time to nursing home admission and death in people with dementia: systematic review and meta-analysis. BMJ 2025;388:e080636.
[6] Buawangpong N, Pinyopornpanish K, Phinyo P, Jiraporncharoen W, Angkurawaranon C, Soontornpun A. Effect of Comorbidities on Ten-Year Survival in Patients with Dementia. J Alzheimers Dis 2023;94:163–75.
[7] Chiari A, et al. How long does it take to diagnose young-onset dementia? A comparison with late-onset dementia. Neurol Sci 2022.
[8] Chun MY, et al. Effects of risk factors on the development and mortality of early- and late-onset dementia: an 11-year longitudinal nationwide population-based cohort study in South Korea. Alzheimers Res Ther 2024;16:92.
[9] GBD. Global mortality from dementia: Application of a new method and results from the Global Burden of Disease Study 2019. Alzheimers Dement (N Y) 2021;7:e12200.
[10] Dang J, Wen Yong AC, Fong ZH, Lyn Ng AS, Ang K. A Systematic Review of Palliative Care Needs in Young-Onset Dementia. J Am Med Dir Assoc 2024:105219.
[11] Day S, et al. Age of Symptom Onset and Longitudinal Course of Sporadic Alzheimer's Disease, Frontotemporal Dementia, and Vascular Dementia: A Systematic Review and Meta-Analysis. J Alzheimer's Dis 2022;85:1819–33.
[12] DerSimonian R, Laird N. Meta-analysis in clinical trials. Control Clin Trials 1986;7:177–88.
[13] Draper B, et al. Time to diagnosis in young-onset dementia and its determinants: the INSPIRED study. Int J Geriatr Psychiatry 2016;31:1217–24.
[14] Gerridzen IJ, Goossensen MA. Patients with Korsakoff syndrome in nursing homes: characteristics, comorbidity, and use of psychotropic drugs. Int Psychogeriatr 2014;26:115–21.
[15] Gerritsen AAJ, Bakker C, Verhey FR, de Vugt ME, Melis RJ, Koopmans RT. Prevalence of Comorbidity in Patients With Young-Onset Alzheimer Disease Compared With Late-Onset: A Comparative Cohort Study. J Am Med Dir Assoc 2016;17:318–23.
[16] Gerritsen AAJ, et al. Survival and life-expectancy in a young-onset dementia cohort with six years of follow-up: the NeedYD-study. Int Psychogeriatr 2019;31:1781–9.
[17] Haaksma ML, et al. Survival time tool to guide care planning in people with dementia. Neurology 2020;94:e538.
[18] Hendriks S, et al. Global Prevalence of Young-Onset Dementia: A Systematic Review and Meta-analysis. JAMA Neurol 2021;78:1080–90.
[19] Hendriks SA, et al. End-of-life treatment decisions in nursing home residents dying with dementia in the Netherlands. Int J Geriatr Psychiatry 2016.
[20] Hendriks SA, Smalbrugge M, Hertogh CM, van der Steen JT. Dying with dementia: symptoms, treatment, and quality of life in the last week of life. J Pain Symptom Manag 2014;47:710–20.
[21] Hendriks SAS, van Gageldonk-Lafeber M, Galindo-Garre AB, Schipper F, Hertogh M, C.P.M.P, van der Steen J. Pneumonia, Intake Problems, and Survival Among Nursing Home Residents With Variable Stages of Dementia in the Netherlands. Alzheimer Dis Assoc Disord 2017.
[22] Hodges JR, Davies R, Xuereb J, Kril J, Halliday G. Survival in frontotemporal dementia. Neurology 2003;61:349–54.
[23] Joling KJ, et al. Time from diagnosis to institutionalization and death in people with dementia. Alzheimer's Dement 2020;16:662–71.
[24] Kandiah N, et al. Cost Related to Dementia in the Young and the Impact of Etiological Subtype on Cost. J Alzheimer'S Dis 2016;49:277–85.
[25] Kay DWK, Forster DP, Newens AJ. Long-term survival, place of death, and death certification in clinically diagnosed pre-senile dementia in northern England: Follow-up after 8–12 years. Br J Psychiatry 2000;177:156–62.
[26] Kessels R, Rensen PC, Y CM, Janssen L. Assessment, diagnosis, care and support for individuals with Korsakoff's syndrome in the Netherlands Évaluation, diagnostic, soins et soutien pour les personnes atteintes du syndrome de Korsakoff aux Pays-Bas. Rev Alcoologie Et Addictologie 2025;80.
[27] Kleinbaum DG. Evaluating the Proportional Hazards Assumption. In Survival Analysis: A Self-Learning Text. New York, NY: Springer New York; 1996. p. 129–69.
[28] Koopmans RTCM, van der Sterren KJMA, van der Steen JT. The 'natural' endpoint of dementia: death from cachexia or dehydration following palliative care? Int J Geriatr Psychiatry 2007;22:350–5.
[29] Li Z, et al. Global Burden of Dementia Death from 1990 to 2019, with Projections to 2050: An Analysis of 2019 Global Burden of Disease Study. J Prev Alzheimers Dis 2024;11:1013–21.
[30] Loi SM, et al. Sex differences in survival in younger-onset dementia. Alzheimer's Dement 2021;17:e051958.
[31] Loi SM, et al. Survival in Huntington's disease and other young-onset dementias. Int J Geriatr Psychiatry 2023;38:e5913.
[32] Manabe T, Fujikura Y, Mizukami K, Akatsu H, Kudo K. Pneumonia-associated death in patients with dementia: A systematic review and meta-analysis. PLoS One 2019;14:e0213825.
[33] Maters J, van der Steen JT, de Vugt ME, Bakker C, Koopmans R. Palliative Care in Nursing Home Residents with Young-Onset Dementia: Professional and Family Caregiver Perspectives. J Alzheimers Dis 2024;97:573–86.
[34] Mulders AJ, Zuidema SU, Verhey FR, Koopmans RT. Characteristics of institutionalized young onset dementia patients–the BEYOnD study. Int Psychogeriatr 2014;26:1973–81.
[35] Picard C, Pasquier F, Martinaud O, Hannequin D, Godefroy O. Early onset dementia: characteristics in a large cohort from academic memory clinics. Alzheimer Dis Assoc Disord 2011;25:203–5.
[36] Reisberg B, Ferris SH, de Leon MJ, Crook T. The Global Deterioration Scale for assessment of primary degenerative dementia. Am J Psychiatry 1982;139:1136–9.

[37] Rhodius-Meester HFM, et al. Survival in memory clinic cohort is short, even in young-onset dementia. J Neurol Neurosurg Psychiatry 2019;90:726–8.
[38] Roβmeier C, et al. How Do Persons with Young and Late Onset Dementia Die? J Alzheimer's Dis 2021;81:843–52.
[39] Seath P, Macedo-Orrego LE, Velayudhan L. Clinical characteristics of early-onset versus late-onset Alzheimer's disease: a systematic review and meta-analysis. Int Psychogeriatr 2023:1–17.
[40] Sun Y, Liu C-C, Li C-Y, Chiu M-J. Survival After the Diagnosis of Mild-to-Moderate Alzheimer's Disease Dementia: A 15-Year National Cohort Study in Taiwan. Int J Geriatr Psychiatry 2024;39:e6152.
[41] Thomas BM, Starr JM, Whalley LJ. Death certification in treated cases of presenile Alzheimer's disease and vascular dementia in Scotland. Age Ageing 1997;26:401–6.
[42] Todd S, Barr S, Roberts M, Passmore AP. Survival in dementia and predictors of mortality: a review. Int J Geriatr Psychiatry 2013;28:1109–24.
[43] van de Veen D, et al. Provisional consensus on the nomenclature and operational definition of dementia at a young age, a Delphi study. Int J Geriatr Psychiatry 2022;37.
[44] van der Steen JT, Mitchell SL, Frijters DH, Kruse RL, Ribbe MW. Prediction of 6-month mortality in nursing home residents with advanced dementia: validity of a risk score. J Am Med Dir Assoc 2007;8:464–8.
[45] van der Steen JT, et al. White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the European Association for Palliative Care. Palliat Med 2014;28:197–209.
[46] van der Steen JT, Ribbe MW, Deliens L, Gutschow G, Onwuteaka-Philipsen BD. Retrospective and prospective data collection compared in the Dutch End Of Life in Dementia (DEOLD) study. Alzheimer Dis Assoc Disord 2014;28:88–94.
[47] van Engelen ME, et al. End Stage Clinical Features and Cause of Death of Behavioral Variant Frontotemporal Dementia and Young-Onset Alzheimer's Disease. J Alzheimers Dis 2020;77:1169–80.
[48] van Vliet D, et al. Prevalence of neuropsychiatric symptoms in young-onset compared to late-onset Alzheimer's disease - part 1: findings of the two-year longitudinal NeedYD-study. Dement Geriatr Cogn Disord 2012;34:319–27.
[49] van Vliet D, et al. Time to diagnosis in young-onset dementia as compared with late-onset dementia. Psychol Med 2013;43:423–32.
[50] van Westendorp S, et al. Exploring the Delivery and Management of Specialised Post-Diagnostic Care and Support in Young-Onset Dementia: A Cross-Sectional Study. Health Serv Insights 2025;18:11786329251388775.
[51] Vossius C, Selbæk G, Šaltytė Benth J, Bergh S. Mortality in nursing home residents: A longitudinal study over three years. PLoS One 2018;13:e0203480.
[52] Wolfson C, et al. A reevaluation of the duration of survival after the onset of dementia. N Engl J Med 2001;344:1111–6.
[53] Yoo MJ, et al. Comparing survival and mortality in patients with late-onset and young-onset vascular dementia. Int Psychogeriatr 2023;35:519–27.
[54] Zheng X, Wang S, Huang J, Li C, Shang H. Predictors for survival in patients with Alzheimer's disease: a large comprehensive meta-analysis. Transl Psychiatry 2024;14:184.