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Original Study

Late-Life Dementia Care: Identifying Distinct Care Patterns in the Last Years of Life



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A B S T R A C T

Keywords:
Dementia
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Objectives: To identify common long-term care patterns in the 6 years before death among individuals aged ≥ 65 years with dementia in the Netherlands and to examine how sociodemographic and health factors are associated with these patterns.

Design: A longitudinal retrospective study was conducted using routinely recorded data for the entire Dutch population on health care use, cause of death, and sociodemographics.

Setting and Participants: We identified 43,578 individuals who passed away in 2021 with dementia based on their use of dementia-related services and recorded cause of death.

Methods: Using ordered logit latent class analysis, we estimated the likelihood of individuals using long-term care (1: no formal LTC; 2: community-based home care services; 3: nursing home care) in each of the 6 years prior to death. Predictors included age, gender, migration background, partner status, polypharmacy, chronic illness groups, homeownership status, and household income quartiles.

Results: Three groups with distinct care patterns were identified: the Late Formal Care Group initially did not receive formal LTC but transitioned to community-based home care services and nursing homes 4 years before death, primarily relying on nursing home care. The Mixed Care Group used community-based home care services 6 years before death and shifted to nursing home care in their final years. A large share of the Early Nursing Home Group already used nursing home care 6 years before death, with nearly all individuals residing in nursing homes during their last 3 years. The Late Formal Care Group typically had higher income, greater homeownership rates, more often had a partner, and exhibited better health than the other groups, which accessed formal care earlier.

Conclusions and Implications: Variations in care patterns highlight that greater socioeconomic resources, stronger support, and better health relate to later formal care use. Understanding these patterns is vital for informed policy planning and resource allocation.

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Dementia leads to a progressive decline in cognitive, physical, and emotional functioning, increasing dependence on others for daily care.¹ As the disease advances, care needs tend to change, often resulting in the use of formal home care or institutional care.^{2–4} In many countries, including the Netherlands, there have been efforts to help older adults remain living at home.⁵ In 2015, the Dutch long-term care (LTC) system

was reformed to promote aging in place by reducing nursing home capacity and expanding home care services.⁶ However, the transition to a nursing home is not solely driven by the availability of formal care but may also be shaped by factors such as the availability of informal care or living conditions.^{7,8} Understanding how individuals navigate the care system and identifying heterogeneity in dementia care patterns is crucial for refining policies and improving the LTC system.

Existing studies have identified the role of individual factors, including dementia type, multimorbidity, polypharmacy, and socioeconomic and demographic characteristics, in determining transitions between different types of care.^{9–13} A recent population-based Dutch study examined variations in care trajectories—covering no formal care, home care, and institutional care—for individuals with dementia diagnosed by general practitioners.¹⁴ This study investigated

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differences in care duration by gender and age, revealing that women generally experience longer care duration than men and that factors such as living alone, migration background, polypharmacy, and income relate to the time spent in each care type. However, focusing on the effects of individual risk factors may oversimplify the complexity of care patterns; it may be particular combinations of factors that influence what type of care individuals use in the last years of life. In this context, a Canadian study captured the complexity of dementia care trajectories using state sequence analysis.¹⁵ This study solely focused on acute care settings—such as hospitalizations and emergency departments—rather than LTC.

Our study analyzes care patterns for individuals with dementia in the last years of life. Using ordered logit latent class analysis, we aim to answer the following question: What are the most common care patterns—including use of no formal LTC, community-based home care services, and nursing home care—in the last 6 years of life for individuals with dementia in the Netherlands, and how are sociodemographic and health factors associated with these patterns? We expect to observe variations in patterns of care use in the final years of life among people with dementia, given the heterogeneity of this population. Specifically, we anticipate more and earlier use of care services among individuals with greater health problems, as well as among those without informal caregivers or with a lower socioeconomic status.

Methods

Study Population

To identify individuals with dementia in the Dutch population, we used administrative data for the entire Dutch population made available by Statistics Netherlands for the years 2017 to 2021. We identified individuals based on their use of dementia-related services, including eligibility for and use of nursing home care, outpatient medication, hospital care, mental health services, and home care, as well as those with dementia listed as a cause of death.^{2,16} Lastly, we accessed patient records from a 10% representative sample of Dutch general practitioners, to include individuals based on diagnosis by the GP.¹⁷ Similar identification methods were used by Klijs et al¹⁸ to identify persons with dementia in the Netherlands and by Taylor et al¹⁹ to identify persons with Alzheimer disease through Medicare claims data in the United States.

For details on the data sources, definitions, and the number of individuals identified by each identification factor, please refer to [Supplementary Table 1](#). Our sample consisted of 43,578 individuals aged 65 years and older with dementia who died in 2021 ([Supplementary Figure 1](#)). This study has been approved according to the governance code of Nivel Primary Care Database, under numbers NZR-00321.048 and NZR-00323.026. The use of electronic health records for research purposes is allowed under certain conditions. When these conditions are fulfilled, neither obtaining informed consent from patients nor approval by a medical ethics committee is obligatory for this type of observational studies containing no directly identifiable data (arr. 24 GDPR implementation Act ja arr. 9.2 sub j GDPR).

Outcomes

We linked our sample to individual-level formal care data (2015–2021) from Statistics Netherlands. In the Netherlands, LTC is funded through 3 systems: (1) social health insurance (ZVW) covers district nursing at home for less intensive medical and personal care; (2) the Long-Term Care Act (WLZ) finances intensive care in nursing homes or home and noninstitutional environments, such as clustered housing or private facilities; and (3) through the Social Support Act (WMO), municipalities fund nonmedical support at home, respite care, temporary shelters, and temporary protected living arrangements for those with psychological or psychosocial issues.

In this study, LTC includes both community-based home care services and nursing home care. We created an ordinal outcome variable to classify annual care use in each of the 6 years before death. The variable had the following values: (1) no formal LTC, (2) community-based home care services, and (3) nursing home care. No formal LTC indicates no recorded LTC use. Community-based home care services include district nursing, WLZ-funded home care, and municipal nonmedical support. Nursing home care covers WLZ-financed care in nursing homes and temporary shelters and protected living arrangements managed by municipalities. If multiple care types were used in a year, only the most intensive type was recorded (nursing home care > community-based home care services > no formal LTC). We chose a 6-year period to avoid overlap with the years prior to the 2015 LTC system reform and to align with median times from dementia diagnosis to death (5.0 years).² See [Supplementary Table 2](#) for details.

Sociodemographic and Health Characteristics

Sociodemographic and health data were obtained from the Municipal Register. Given dementia's progressive nature, aging increases reliance on formal care.^{1,2} Age was categorized based on age 6 years before death: 59–68, 69–78, 79–88, and 89 years. Gender was included, as older men with dementia typically have shorter care durations than women.^{14,20,21} Migration background—Dutch, European (excluding the Netherlands), or non-European—was included, as non-Western migrants often face reduced care access.²² Partner status (married or registered partnership) was assessed 6 years before death, as partners can delay formal care needs through informal support.^{23,24}

Health indicators, including polypharmacy (≥ 5 prescribed medication types) and chronic illnesses, were analyzed because of their link with worse dementia outcomes and higher care use.^{25–27} Chronic conditions were identified using a medication-based mapping technique (see [Supplementary Table 3](#)) and categorized as none, 1 or 2, 3 or 4, and more than 4, reflecting the increasing prevalence of multimorbidity in patients with dementia.^{28,29} Both health indicators were assessed in 2011—that is, 10 years before death—because of missing medication data for institutionalized individuals. By 6 years before death, some individuals may have already been in nursing homes, and chronic conditions often develop earlier in life.³⁰

Economic factors, including income and homeownership, may influence nursing home admissions, given the link between health and wealth.^{31–33} Homeownership may also relate to greater access to resources supporting independent living, such as housing adaptations.³⁴ Household income was divided into quartiles based on levels 6 years prior to death, excluding extreme outliers (below €0 or above €1,000,000). We used homeownership status (house owner vs renter) 10 years prior to death (2011) to capture the ownership situation prior to a potential move to a nursing home.

Statistical Analysis

We conducted an ordered logit latent class analysis to estimate the likelihood of individuals with dementia using LTC (1: no formal LTC; 2: community-based home care services; 3: nursing home care) in each of the 6 years before death. We modeled these outcomes based on an individual's unobserved (latent) state or "class" in each of the last 6 years of life using 6 Ordered Logit models. This approach enables the identification of distinct dementia care patterns inferred from the data rather than based on directly observed characteristics. Individual's class membership was fixed over time and was modeled to depend on the above-defined predictors using a multinomial logit. The model was estimated in STATA (version 16) using the `gsem` command. A detailed description of the model is provided in [Supplementary Material](#). To determine the optimal number of latent classes, we used Akaike information criterion and Schwarz's Bayesian

information criterion. After estimating the model, we assigned class membership to each individual based on posterior probabilities using the `classposteriorpr` command. Posterior probabilities represent the likelihood of an individual belonging to a class, given their observed characteristics, with the highest estimated probability among the classes determining the specific class membership.

We performed 3 robustness checks to assess the sensitivity of our results to data limitations. First, we addressed the potential overlap between dementia identification and care outcomes, as the care use patterns may be influenced by the way in which people with dementia were identified. For example, individuals identified as having dementia based on their use of dementia-related nursing home care are likely observed in advanced stages, making it their final care setting. We therefore performed a subgroup analysis for individuals with a dementia-related cause of death, eliminating any overlap between how individuals with dementia were identified and health care use (see [Supplementary Material](#) for details).

Second, we lacked data on specific dementia subtypes, which may show different care patterns. To address this, we created proxies for Alzheimer disease, vascular dementia, and Lewy body dementia using medication data and examined care use variations among these subtypes (see [Supplementary Material](#) for details).^{35–37}

Third, because our observation period (2015–2021) includes 2 years during the COVID-19 pandemic, we recognize that the pandemic may have affected decisions regarding different types of care. To account for this, we conducted a similar analysis for individuals who passed away prior to the pandemic (in 2019, rather than 2021). This allowed us to examine LTC use between 2015 and 2019, isolating the prepandemic period and assessing the impact of COVID-19 on care use.

Results

Sample Characteristics

[Figure 1](#) shows the distribution of care types in the years before death (see [Supplementary Table 5](#)). Six years prior, 65.6% received no formal LTC, 22.6% used community-based home care services, and 11.8% were in nursing homes. By the final year, 69.7% were institutionalized in nursing homes, and 7.0% received no formal LTC.

Community-based home care services usage slightly increased but was often replaced by nursing home care near death. For sample characteristics, see [Supplementary Table 6](#).

Latent Class Analysis

We chose a 3-class model, as it provided the lowest values of the information criteria (Akaike information criterion = 344,753; Bayesian information criterion = 345,222; see [Supplementary Table 4](#)) compared with 1 or 2 classes. To describe the groups based on care use before death, we included intuitive names: the *Late Formal Care Group*, the *Mixed Care Group*, and the *Early Nursing Home Group*. [Figure 2](#) and [Supplementary Table 7](#) illustrate the dementia care patterns for these groups, showing their care use in the years before death (see [Supplementary Table 7](#) for details).

In the Late Formal Care Group (41.5% of the sample), almost no individuals used formal LTC 6 years before death ($P = .99$, 95% CI .98–.99). The probability of using community-based home care services or nursing home care rose 4 years before death, with a majority eventually transitioning to nursing homes ($P = .55$, 95% CI .55–.56). In the Mixed Care Group (27.6% of sample), the probability of using community-based home care services was .51 (95% CI .50–.56) 6 years before death, whereas the probability of not receiving formal LTC was .47 (95% CI .46–.48). As death approached, the probability of not using formal LTC dropped sharply to nearly zero ($P = .00$, 95% CI .00–.01). Community-based home care services use initially increased, stabilized, and then decreased, whereas nursing home care started to rise 3 years before death, with the probability reaching .57 (95% CI .57–.58) in the final year of life. In the Early Nursing Home Group (30.9% of sample), the probability of nursing home care 6 years before death was already .36 (95% CI .36–.37), rising rapidly so that nearly all individuals resided in nursing homes during the last 3 years ($P > .99$, 95% CI .99–1.00).

Class Characteristics

[Table 1](#) presents the demographic, health, and socioeconomic characteristics of each group. The Late Formal Care Group was the most advantaged, with most individuals in the top income quartile, highest homeownership, and partnership rates, along with the lowest

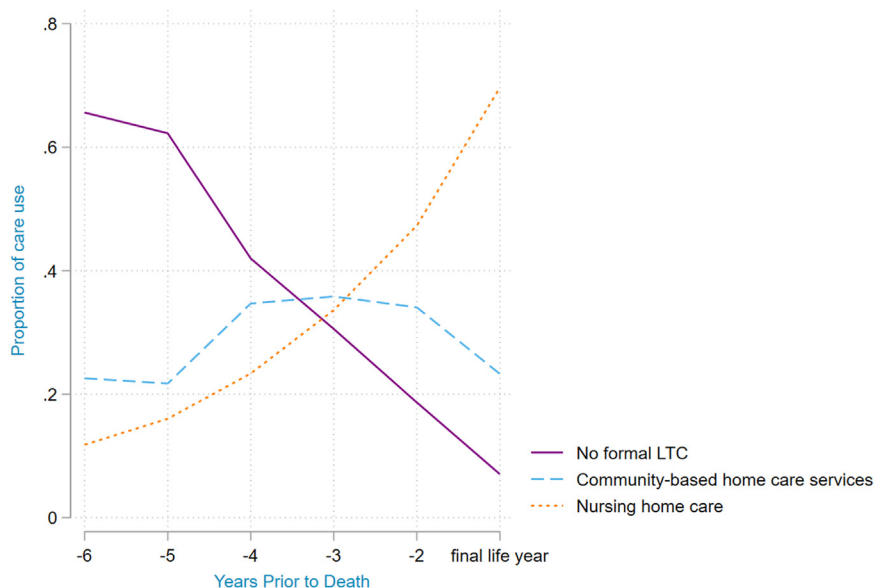


Fig. 1. Long-term care types used over the 6 years before death among individuals with dementia. Proportion of individuals receiving no formal LTC (purple), community-based home care services (blue), and nursing home care (orange) each year over the 6 years before death in the dementia population.

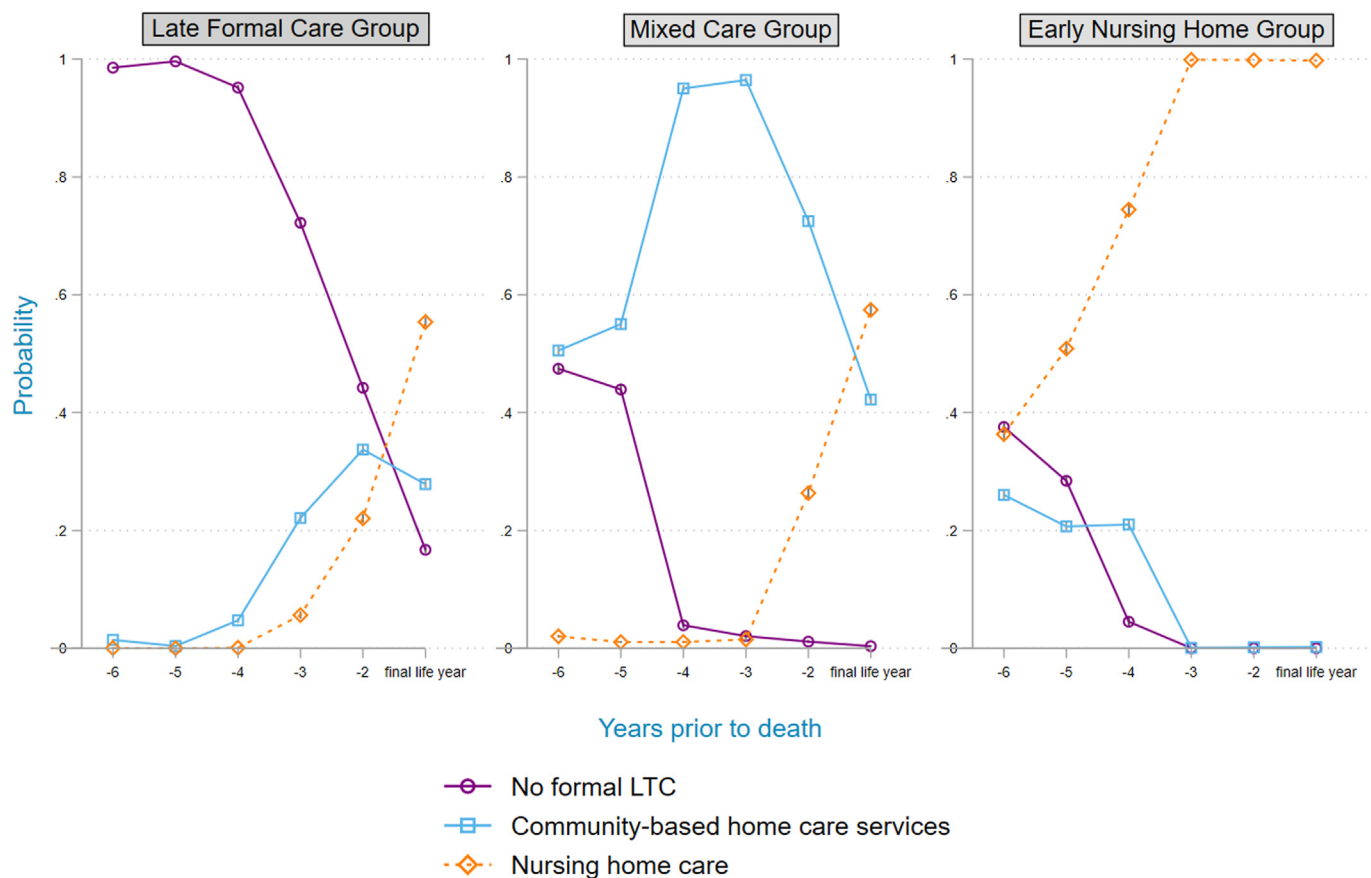


Fig. 2. Probability of dementia care use in the years before death across 3 distinct groups of individuals with dementia. Probability of using no formal LTC (purple), community-based home care services (blue), and nursing home care (orange) each year over the 6 years before death for each Latent Care Group (Late Formal Care, Mixed Care, and Early Nursing Home) in the dementia population.

polypharmacy levels and fewer chronic conditions. This indicates that individuals who use less formal care in their last years of life tend to be healthier, enjoy greater support, and are more socioeconomically secure.

The Mixed Care Group included individuals with a higher reliance on care. They exhibited higher rates of polypharmacy and chronic illnesses compared with the other groups. Socioeconomically, this group was more disadvantaged than the Late Formal Care group, with fewer individuals in the top income quartile and lower homeownership. Moreover, fewer individuals in this group had a partner.

The Early Nursing Home Group stood out as the most vulnerable. They were the most disadvantaged economically, with the majority in the lowest income quartile and the lowest homeownership rates. Healthwise, this group was older and showed high levels of polypharmacy and chronic illness, highlighting their extensive care needs. Also, this group was predominantly female and had the lowest proportion of partners for potential support. The differences in the characteristics were also reflected in the coefficients determining class membership (see [Supplementary Table 8](#)).

Robustness Checks

When rerunning the analysis using a sample of individuals identified as having dementia based on their cause of death ($n = 14,299$), the care patterns were comparable to the main analysis. This provides evidence that the observed care patterns were not driven by the way the sample was constructed (see [Supplementary Material](#)).

Furthermore, [Supplementary Material](#) shows the proportion of dementia proxy types in each care pattern group, with Alzheimer disease predominating across all groups, followed by vascular and

Lewy body dementia. The comparable distribution of dementia subtypes across classes suggests that care patterns were not mainly driven by dementia type. [Figure 3](#) separately depicts no formal LTC, community-based home care services, and nursing home care use over the 6 years before death for individuals who are likely to have Alzheimer disease ($n = 17,671$), vascular dementia ($n = 10,085$), or Lewy body dementia ($n = 6010$) (see [Supplementary Material](#)). Although individuals with Alzheimer disease used formal care more frequently and were, therefore, more often in the Early Nursing Home Group, we again observed similar patterns of care use over time across all types of dementia, as well as variations in these patterns that are independent of the condition. Hence, as these patterns largely mirror those of the overall population ([Figure 1](#)), dementia subtypes do not seem to impact care patterns greatly.

Finally, when comparing LTC use in the years prior to death for individuals who died in 2019 (pre-COVID-19) with those who died in 2021, we found that the care types used were largely similar. In the 2 final life years, during the COVID-19 pandemic, our main 2021 sample showed a slight increase in home care compared with the 2019 sample, but overall care proportions remained nearly the same (see [Supplementary Material](#)).

Discussion

Main Findings

This study identified common care patterns for individuals aged ≥ 65 years with dementia in the 6 years preceding death and examined how sociodemographic and health factors influenced these

Table 1
Demographic, Health, and Socioeconomic Characteristics per Dementia Care Pattern Group

Characteristics	Late Formal Care Group, % (n = 18,087)	Mixed Care Group, % (n = 12,022)	Early Nursing Home Group, % (n = 13,469)
Age 6 y before death			
59–68 y	8.7	5.1	4.9
69–78 y	39.7	22.9	21.6
79–88 y	46.7	57.5	55.7
89 y and older	4.9	14.4	17.9
Gender			
Female	45.3	66.5	74.1
Partner status			
Having partner 6 y before death	64.3	35.7	30.7
Migration background			
Netherlands	86.6	85.0	87.9
European Union (excl. NL)	6.9	7.0	6.8
Other	6.5	8.0	5.3
Polypharmacy status			
Use of ≥ 5 medications 10 y before death	49.4	65.1	55.6
Chronic illnesses 10 y before death			
0	15.7	8.7	14.4
1–2	39.5	31.5	34.5
3–4	32.1	36.8	32.7
>4	12.7	23.0	18.5
Housing status			
Living in owner-occupied house 10 y before death	57.3	39.3	35.2
Household income 6 y before death			
Q1 (lowest)	16.2	27.8	35.4
Q2	21.4	29.3	26.1
Q3	28.0	23.5	22.3
Q4 (highest)	34.4	19.4	17.3

patterns. We identified 3 groups with different patterns of care: the Late Formal Care Group, which did not use formal LTC until the last few years before death; the Mixed Care Group, which initially relied on community-based home care services and shifted to nursing homes in their final years; and the Early Nursing Home Group, with a strong dependence on nursing home care in all 6 years before death, and nearly all individuals residing in nursing homes during their last 3 years of life. Class membership was associated with income, availability of partners, and health status. The Late Formal Care Group had higher incomes, higher homeownership rates, and were more likely to have a partner and to be in better health compared to the other groups.

Comparison With Previous Research

Our study demonstrates that socioeconomic and health factors relate to care patterns for individuals with dementia, with those in more advantageous positions using less formal care. Specifically, we observed that healthier individuals tend to use less formal care, whereas those with greater health problems transition to formal care earlier. This finding aligns with prior research linking polypharmacy to increased frailty and care dependency.^{38,39} We further found that the absence of a partner accelerates the need for formal care, likely due to the reduced availability of informal caregiving. Existing literature supports this, indicating that limited informal care increases reliance on formal services and raises the risk of institutionalization.^{23,40,41} Higher income and homeownership were also associated with lower formal care use. These findings are consistent with studies linking lower income to poorer health and greater care needs.^{31,42,43} Moreover, existing evidence suggests that homeowners may use the prospect of a bequest to encourage informal caregiving, thereby delaying institutionalization.⁴⁴ Additionally, homeowners' preference to age in place and satisfaction with their living conditions likely contribute to postponed nursing home admission.⁴⁵

Strengths and Limitations

The present study had several strengths. First, our ordered logit latent class analysis identified specific combinations of risk factors affecting care patterns rather than summing individual factors. This approach revealed that even when individuals had similar observable characteristics, their care patterns differed because of combinations of factors. Second, we used multiple data sources (dementia-related care, cause of death) to identify individuals with dementia, rather than relying on a single data source or a formal diagnosis. Because many individuals with dementia lack a formal diagnosis or face diagnostic delays,^{46–49} this approach reduces the risk of missing a significant portion of the dementia population. For instance, in our sample 8227 dementia cases were identified through general practitioners, highlighting cases that would be missed if only GP records were used. Third, our findings extend beyond the Netherlands, offering valuable insights for countries facing similar challenges with the rising prevalence of dementia and the shift toward aging in place. As seen in initiatives like the United States' Home and Community-Based Services through the Medicaid Aging Waiver program, understanding the care needs of people with dementia at the end of life has become increasingly important. Our findings underscore the heterogeneity within this population, showing that care use is influenced not only by health status but also by socioeconomic factors and the availability of informal caregivers. Although the organization of care varies across countries, these underlying patterns are relevant in diverse contexts. However, the way these factors translate into care provision depends on country-specific systems, making the Dutch context important for interpreting our results.

This study also had limitations. We lacked detailed data on the exact onset, subtype, or progression of dementia. However, robustness checks using proxies for the 3 most common dementia types among our age group, indicated that although individuals with Alzheimer disease used more formal care, care patterns over time and their variations were largely independent of the dementia type. Moreover, a potential overlap between dementia identification and care outcomes

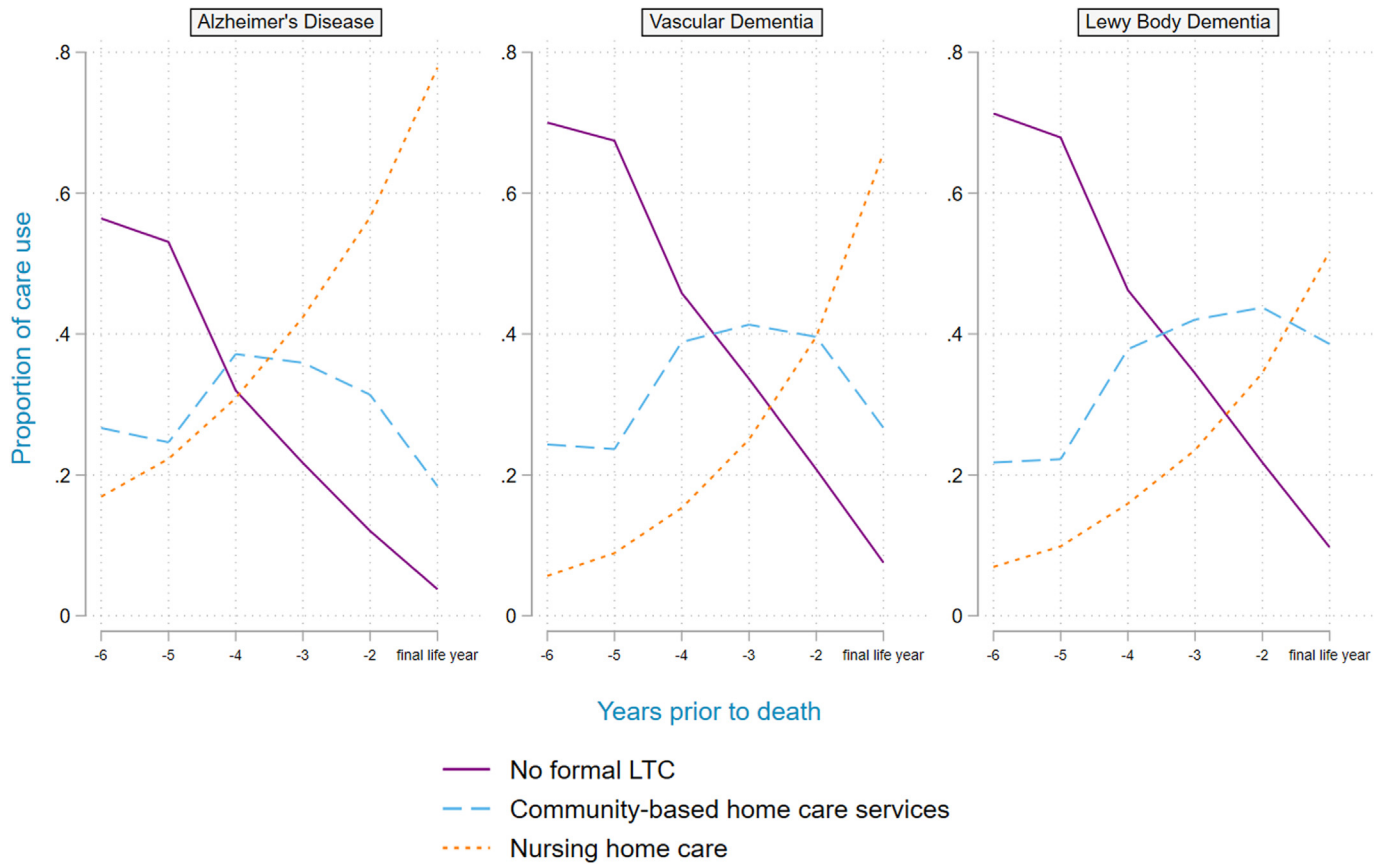


Fig. 3. Proportion of long-term care use over the 6 years before death by dementia type. Proportion of individuals receiving no formal LTC (purple), community-based home care services (blue), and nursing home care (orange) each year over the 6 years before death for those identified with proxies for Alzheimer disease, vascular dementia, and Lewy body dementia.

exists, as some individuals were identified through care use, which could influence care patterns. To address this, we conducted a subgroup analysis of individuals identified through cause-of-death records to eliminate direct overlap, finding similar care utilization trends to the overall dementia sample. Furthermore, as our observation period included 2 years of the COVID-19 pandemic—a time that was particularly disruptive for community-dwelling older adults and nursing home residents — care decisions during this period may have been affected. Nursing home admissions dropped among people with dementia but returned to prepandemic levels after the first wave.⁵⁰ These disruptions may have led some individuals to remain at home longer. By comparing annual end-of-life care use in our full sample with a subsample of individuals who died before the pandemic in 2019, we observed a slight increase in the use of community-based home care services. However, overall care patterns remained similar, suggesting that the pandemic did not substantially alter broader care trends for individuals with dementia. Finally, no data on informal care use were available. However, individuals with greater access to potential caregivers (eg, having a partner) were more likely to belong to the Late Formal Care Group, emphasizing the role of informal care for those with dementia.

Conclusions and Implications

We identified care patterns for individuals aged ≥ 65 years with dementia during the 6 years before death and examined how socio-demographic and health factors influence them. Factors related to the later onset of formal care use included greater socioeconomic resources, availability of a partner, and better health. Understanding

these dementia care patterns is crucial for policy makers to improve planning and resource allocation for the growing group of older people with dementia.

Declaration of Generative AI and AI-Assisted Technologies in the Writing Process

During the preparation of this work the authors used ChatGPT in order to improve language and readability. After using this tool/service, the authors reviewed and edited the content as needed and takes full responsibility for the content of the publication.

Disclosure

The authors declare no conflicts of interest.

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Supplementary Data

Supplementary data related to this article can be found online at <https://doi.org/10.1016/j.jamda.2025.105699>.

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