



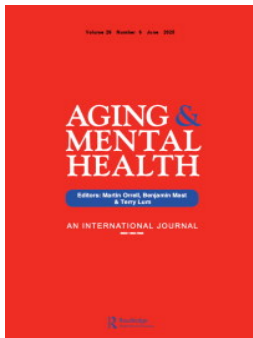
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Factors influencing time to support in young-onset dementia: survival analysis of data from the Swedish Dementia Registry (SveDem)

F. Kårelind^a, L. Johansson^a, S. Zarit^{b,d,e}, H. Wijk^{c,f}, T. Bielsten^a and D. Finkel^{a,d}

^aStudies on Integrated Health and Welfare (SIHW), Institute of Gerontology, School of Health and Welfare, Jönköping University, Jönköping, Sweden; ^bInstitute of Gerontology, School of Health and Welfare, Jönköping University, Jönköping, Sweden; ^cInstitute of Health and Care Science, The Sahlgrenska Academy at Gothenburg University, Gothenburg, Sweden; ^dCenter for Economic and Social Research, University of Southern California, Los Angeles, CA, USA; ^eDepartment of Human Development and Family Studies, Penn State University, University Park, PA, USA; ^fDepartment of Architecture and Civil Engineering, Chalmers University of Technology, Gothenburg, Sweden

ABSTRACT

Objectives: Understanding the timing of service access for persons with young-onset dementia is essential for developing adequate support. This study aims to describe the formal support available for persons with young-onset dementia in Sweden and identify factors influencing its provision over time.

Method: A prospective cohort study was carried out using data from the Swedish Dementia Registry (SveDem), focusing on persons diagnosed with young-onset dementia between January 2009 and April 2022 ($n=2592$). Descriptive statistics provided a comprehensive overview of the population, and Cox Regressions were used to analyse factors associated with the time to receive support services post-diagnosis.

Results: Living with another adult and higher MMSE scores were significantly associated with later access to home help services ($p < 0.001$) and care facilities ($p < 0.001$). Higher MMSE scores ($p < 0.001$), older age ($p = 0.023$), living with another adult ($p = 0.010$) and diagnosis at primary care centres ($p = 0.016$) were also associated with later access to day-care services. No significant associations were found between age, sex, medications, care setting, living arrangement, or MMSE score or with the time to access counselling services.

Conclusion: The timing of access to support services for persons with young-onset dementia varies significantly, particularly for those living with another adult. These patterns may reflect a hidden caregiver burden.

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KEYWORDS

Dementia care; memory clinics; young-onset dementia; YOD; SveDem

Introduction

Young-onset dementia

Young-onset dementia, defined as dementia onset before age 65 (Ducharme & Dickerson, 2015; van de Veen et al., 2022), affects approximately 3.9 million persons globally (Hendriks et al., 2021), including 9,500–12,000 in Sweden (Hendriks et al., 2021; Skovdahl et al., 2017). The term young-onset dementia is increasingly preferred over early-onset dementia, as the latter may be misinterpreted as referring to the early stages of dementia rather than the age of onset. The age cut-off for young-onset dementia is not based on biological processes but reflects psychosocial distinctions, such as the typical retirement age (van de Veen et al., 2021).

Alzheimer's disease is the most common diagnosis in young-onset dementia, although frontotemporal dementia and vascular dementia occur frequently. Persons with young-onset dementia often present atypical symptoms, such as depression and behavioural changes (Draper & Withall, 2016; Ducharme & Dickerson, 2015), which, when unrecognised, can delay diagnosis (Chirico et al., 2022; Rabanal et al., 2018). As a result, persons with young-onset dementia may experience a delay in the onset of essential support services.

Support services for young-onset dementia

An important framework for understanding the psychosocial challenges of young-onset dementia is Neugarten's concept of 'off-time' events—that is, life events that occur at an unexpected time in the lifespan (Neugarten, 1970). Off-time events disrupt a person's expectations for the course of their life trajectory. For persons with young-onset dementia, the condition typically arises during a period of life associated with career advancements and family responsibilities. The 'off-time' occurrence of an illness associated with old age disrupts the expectations that persons with young-onset dementia have for the course of their lives and likewise upsets the expectations of their families. The unexpected timing of young-onset dementia can delay families in seeking formal support services. Furthermore, since dementia is usually associated with a later onset, a younger onset can be surprising and challenging to diagnose. This often leads to misdiagnosis (Chirico et al., 2022; O'Malley et al., 2021), further complicating access to necessary services and support. Consequently, the unexpected event of a dementia diagnosis may lead to a delay in obtaining important formal support services.

Young-onset dementia significantly affects quality of life (Baptista et al., 2016), presenting unique challenges compared

CONTACT F. Kårelind  fanny.karelind@ju.se

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to late-onset dementia. These challenges include disruptions in family dynamics, as persons may have dependant children or ageing parents, and financial strain caused by reduced income or early retirement (Bannon et al., 2022; Draper & Withall, 2016). Involuntary early retirement can also lead to feelings of loss and identity disruption (Aspö et al., 2023; Rabanal et al., 2018). The emotional and practical demands of these changes extend beyond the person, placing a considerable burden on informal caregivers (Dixit et al., 2018; Gelman & Rhames, 2020; Lim et al., 2017), who often face significant psychological distress (Wong et al., 2020) and must navigate challenges such as behavioural symptoms (Lim et al., 2017) and social stigma (Chirico et al., 2022).

Providing meaningful, tailored activities for persons with young-onset dementia is critical for managing symptoms and maintaining independence (Aspö et al., 2023; Giebel et al., 2020; Stamou et al., 2023). Tailored community groups and peer support programs can foster connection, coping strategies and independence for both the person and their family (Rabanal et al., 2018; Stamou et al., 2022, 2023). However, many existing services are designed for older adults, limiting their relevance and effectiveness for younger persons (Giebel et al., 2020).

Despite increasing research, knowledge about the formal support services needed and used by persons with young-onset dementia remains limited. Previous studies have highlighted barriers such as reluctance to accept help by persons with young-onset dementia and their informal caregivers, who often strive to maintain normalcy (Cations et al., 2017; Hendriks et al., 2023). Non-acceptance of services may act as a coping strategy (Wawrziczny et al., 2016), but continuously offering formal support remains important, even when it is not immediately utilised (Rabanal et al., 2018).

Formal support for persons with young-onset dementia plays a critical role, especially if it has the potential to improve coping abilities and independence. However, this area is poorly understood. Research from the Netherlands provides some context; one study revealed that day-care services for persons with young-onset dementia are typically accessed within two years of diagnosis, while long-term care facilities are more commonly utilised after four to five years (Hendriks et al., 2023). Another earlier study reported that the average time to institutionalisation for persons with young-onset dementia is approximately nine years from symptom onset (Bakker et al. 2013). While these studies offer some insight, a research gap persists. To address this gap, the present study uses data from the Swedish Dementia Registry (SveDem) to examine the formal support available for persons with young-onset dementia in Sweden and identify factors influencing its provision over time.

Methods

Research context

In Sweden, healthcare is managed by regions and municipalities. Regions manage in- and outpatient healthcare, while municipalities provide social services and home healthcare. Dementia care is guided by three key laws: the Health and Medical Care Act (HSL), the Social Services Act (SoL), and the Act on Support and Service for Persons with Certain Functional Impairments (LSS). These laws facilitate formal support services, such as memory clinics, day-care centres, home help, support groups, educational programs, and respite care, to support persons with young-onset dementia.

Swedish national dementia guidelines recommend best practices for diagnosing, treating, and supporting persons with young-onset dementia. They emphasise the importance of regular follow-up at least annually to ensure ongoing care (National Board of Health and Welfare, 2017). The Swedish Registry of Cognitive/Dementia Disorders [SveDem], established in 2007, monitors the implementation of these guidelines and collects data from specialist units, primary care centres, care facilities and home health care. With over 100,000 entries, SveDem supports research and monitors guideline implementation, covering all memory clinics and 78% of primary care units in Sweden (Religa et al., 2015; Swedish Registry for Cognitive/Dementia Disorders (SveDem), 2021).

Study design

This prospective cohort study examines baseline and longitudinal data of persons under 65 at the time of entry in SveDem, covering data recorded from January 2009 to April 2022. Initially, there were 4458 persons in this age group in SveDem. Baseline data were missing for 208 persons and were therefore excluded, leaving a cohort of 4250 persons for analysis. Additionally, persons who did not have at least one follow-up entry in the dataset were removed, resulting in a sample size of 2603 persons. Entries with 2 days or less between updates were considered data entry errors and excluded. The remaining dataset consisted of 2592 persons with a baseline entry in the registry, with 2283 from memory clinics and 309 from primary care centres. For those not receiving a follow-up within the study period, 610 persons (37%) died, and 208 persons (12.6%) were diagnosed within 12 months of the end date of the study period.

Local users, typically nurses or physicians, enter the relevant data into SveDem. They rely on the patient's medical records as the primary source of information. If information is not documented in the medical records, it is considered 'not performed' in SveDem (Religa et al., 2015). The collected data included demographics, medication records, cognitive function, housing status, and support interventions (Supplementary Table 1).

SveDem variables

The study examined various characteristics that describe the sample population. These characteristics were used to determine if specific attributes, such as age, sex, living situation, care setting, level of functioning and the number of medications (as a proxy for general health), were associated with using support services. Measures of support in this study included day-care, accommodation, home help service and counselling. These variables are measured in the SveDem registry at baseline and every follow-up. At baseline entry in the registry, support measures indicate types of support the person already has at the time of diagnosis, while follow-up entries in the registry capture support after diagnosis. For counsellor support, baseline data only indicate whether such support was offered, as information about whether it was obtained is unavailable.

Data analysis

Descriptive statistics (Table 1) were used to provide an overview of the sample and emphasise its key characteristics. These included measures of central tendency, such as means and

median, to illustrate average values and measures of variability, such as standard deviation and range.

A Cox regression survival analysis was conducted to examine time-to-event data and identify factors associated with the timing of receiving support services post-diagnosis (Supplemental Table 2). The first support onset was used as the event of the analysis. For each analysis, persons who had already obtained services at baseline were excluded. The primary time-to-event variable in this study was the time to the 'first support onset', defined as the date when the support was first recorded in SveDem. If the person was never offered support, the time of last entry in the registry was used as the end of follow-up. Variables with more than two categories, such as accommodation options, were dichotomised due to inconsistencies in the availability of specific response options over the study period. Dichotomisation ensured the inclusion of all available data and maintained consistency for analysis over the 13-year study period.

Each model assessed the impact of various predictors on the number of days it took to receive post-diagnostic support. Censored data were observations where the event (support) did not occur by the last recorded entry in the registry, assuming non-informative censoring. We evaluated the proportional hazards assumption by examining cumulative hazard plots, which showed approximately parallel curves, indicating no considerable violations. This method is consistent with standard

practices in survival analysis, where visual inspection of cumulative hazard functions is a recognised approach for assessing proportionality (Bewick et al., 2004).

The hazard ratios were presented, with values less than 1 indicating a later onset of support. Confidence intervals were calculated for all hazard ratios to estimate the precision and reliability of these results. The chi-square statistic was used to assess the overall fit of the Cox regression model. A significance level of 0.05 was chosen to determine statistical significance.

Results

Demographic data

The mean number of follow-up entries recorded in the registry was 2.6 (SD 1.8), with a median of 2 entries, spanning a range from 1 to 14. The mean days between entries were 424 days, with 75% of the sample having a 456-day gap or less and 50% having a 364-day gap or less (between 17 and 3900 days). The mean days between diagnosis and first follow-up were 394 days and between follow-up one and follow-up two, 431 days.

Table 1 presents an overview of the study population's baseline characteristics. Women comprised a slight majority of the sample population, making up 53.5%. Most of the sample fell within the 60–64 age bracket (58%), followed by those aged 55–59 (28.6%). On average, the age at diagnosis was 59.3 years (SD 4.4), with a median of 60 years and a range of 25 to 64 years. Most persons lived with another adult (72.1%), while only a small number resided in care facilities (4.1%).

Regarding diagnosis, Alzheimer's disease was the most prevalent, accounting for 58.2% of the sample, followed by unspecified dementia (12.1%) and vascular dementia (8.7%). On average, persons were prescribed 3.8 medications (SD 3.02), with a median of 3 and a range from 0 to 22. The mean MMSE score was 22.5 (SD 4.9), with a median of 23 and a range from 3 to 30 points. Finally, most persons (88.1%) were entered into the registry by memory clinics.

Support

Table 2 presents support already in place at the time of diagnosis and support services obtained and implemented during the study period. Regarding existing support at the time of diagnosis, only a small percentage of the sample had day-care services (2.3%) or home help services (7.7%). Almost half of the sample (46.0%) had been offered contact with a counsellor at the time of diagnosis.

As for support obtained during the study period, day-care was the most frequently used service (26.5%), followed by home help service (22.8%). Counsellor services were obtained for 19.6% of the sample, and a small portion of the sample moved to care facilities (11.3%). The mean number of days before any

Table 1. Characteristics at baseline data entry ($n = 2592$).

	<i>N</i> (valid per cent)	Mean (SD)
Age at diagnosis ($n = 2592$)		59.3 (4.4)
25–29	1 (0.04)	
30–34	4 (0.2)	
35–39	6 (0.2)	
40–44	12 (0.5)	
45–49	50 (1.9)	
50–54	264 (10.2)	
55–59	741 (28.6)	
60–64	1514 (58.4)	
Sex ($n = 2592$)		
Female (1)	1386 (53.55)	
Male (2)	1206 (46.5)	
Dementia diagnosis ($n = 2590$)		
Mixed dementia	114 (4.4)	
Dementia unspecified	313 (12.1)	
Alzheimer's disease	1507 (58.2)	
Dementia in Parkinson's disease	52 (2.0)	
Frontotemporal dementia	211 (8.1)	
Lewy body dementia	57 (2.2)	
Alcohol dementia	41 (1.6)	
Other dementia	72 (2.8)	
Vascular dementia	223 (8.7)	
Medications ($n = 2492$)		3.8 (3.02)
0 Medications	121 (4.9)	
1–2 Medications	937 (37.6)	
3–5 Medications	869 (34.9)	
6–9 Medications	440 (17.7)	
≥10 Medications	125 (5.0)	
MMSE score ($n = 2336$)		22.5 (4.9)
≤9	70 (3.0)	
10–18	622 (26.6)	
19–23	779 (33.3)	
24–30	865 (37.0)	
Accommodation ($n = 2585$)		
Ordinary housing (0)	2467 (95.4)	
Care facility, temporary (1)	37 (1.4)	
Care facility, permanent – not adapted (1)	69 (2.7)	
Care facility, permanent-adapted (1)	12 (0.5)	
Living arrangements ($n = 2497$)		
With another adult (1)	1801 (72.1)	
Living alone (0)	696 (27.9)	
Care setting ($n = 2592$)		
Primary care centres (1)	309 (11.9)	
Memory clinics (0)	2283 (88.1)	

Table 2. Support for persons with young-onset dementia ($n = 2592$).

	Support received (<i>N</i>)	Valid per cent (%)
Support at baseline		
Home help service ($n = 2550$)	196	7.7
Daycare ($n = 2522$)	59	2.3
Counsellor ($n = 2509$)	1192	47.5
Care facility ($n = 2585$)	118	4.6
Support at follow-up		
Home help service ($n = 2534$)	537	22.8
Daycare ($n = 2463$)	653	26.5
Counsellor ($n = 1317$)	258	19.6
Care facility ($n = 2467$)	280	11.3

record of support was 490 days for counselling, 775 days for day-care, 856 days for home help service and 996 days for care facility.

Cox regression survival analysis

Supplemental Table 2 presents the results of four regression models, incorporating six different personal characteristics, to understand the timing of post-diagnostic support for persons with young-onset dementia. Each model's total number of cases and degrees of freedom are presented. Figure 1 shows the hazard plots for all support variables. These plots compare the hazard rates between two dichotomised groups, highlighting differences in risk over time.

When examining the time needed to obtain home help services, MMSE scores were significantly associated with the timing of receiving support, indicating that persons with higher MMSE scores obtained home help later. Additionally, living arrangements showed a significant association with the timing of home help services, suggesting that living with someone was associated with accessing home help later compared to living alone.

Regarding the time to move to a care facility, lower MMSE scores were associated with earlier use of care facilities. Living arrangements were also associated with when care facilities were accessed, as those living with someone accessed these services later than those living alone.

No significant associations were found between receiving counsellor services and age, sex, medications, care setting, living arrangement, or MMSE score, suggesting no evidence of sample characteristics impacting access to these services.

A significant association was found between MMSE scores and access to day-care services, indicating that persons with higher MMSE scores accessed these services later. Significant associations were also observed for living arrangements, as persons living with another adult obtained day-care services later than those living alone. Additionally, age was associated with access to day-care services, with older persons receiving these services at a later time. Finally, being diagnosed in primary care centres was associated with obtaining day-care services later.

Discussion

This study examined the timing of formal support services for persons with young-onset dementia in Sweden and identified

factors influencing their access over time. Key findings revealed that living arrangements significantly influenced the timing of accessing support services, with persons living with another adult obtaining home help, day-care, and care facility services later than those living alone. Additionally, substantial intervals existed before services, such as day-care and home help, were accessed post-diagnosis. Gaps in follow-up care were also evident, with most persons not receiving follow-up appointments within the recommended timeframe.

Post-diagnosis, the time to access support services were notably long. This study observed periods extending over two years before accessing day-care and home help services and more than a full year for access to counselling services. The order in which support is accessed and the relatively short intervals between accessing day-care and moving to a care facility could indicate that home-based support may be introduced too late, making institutionalisation unavoidable. Most persons in the sample did not receive a follow-up appointment even though National dementia guidelines recommend annual follow-ups (National Board of Health and Welfare, 2017). This finding is consistent with an Australian cohort study in which 54% of persons with young-onset dementia were not followed up (Loi et al., 2021). Despite the differences in healthcare system and welfare models between Sweden and Australia, the results underscore a shared challenge in adequate follow-up care for persons with young-onset dementia. These findings highlight the need for improved follow-up care for persons with young-onset dementia.

Living arrangements significantly influenced the timing of support services. Most persons in the sample lived with another adult (72.1%). While the registry does not specify whether this person is an adult child, parent or partner, data from Statistics Sweden (2019) indicate that approximately 70% of all people aged 40–65 in Sweden live with a partner. This suggests that most persons with young-onset dementia in this age range likely reside with a partner rather than a parent or adult child. Persons living with another adult accessed home help services, care facilities, and day-care later than those living alone. This might reflect informal caregiving, where cohabiting family members fulfil support needs. It may also be influenced by legislation, such as the Marriage Code (The Marriage Code, 1987), which emphasises that married couples are expected to care for each other's household needs, potentially limiting access to certain formal support services. A recent study highlighted that nearly 60% of family members spend over 5 h per day caring

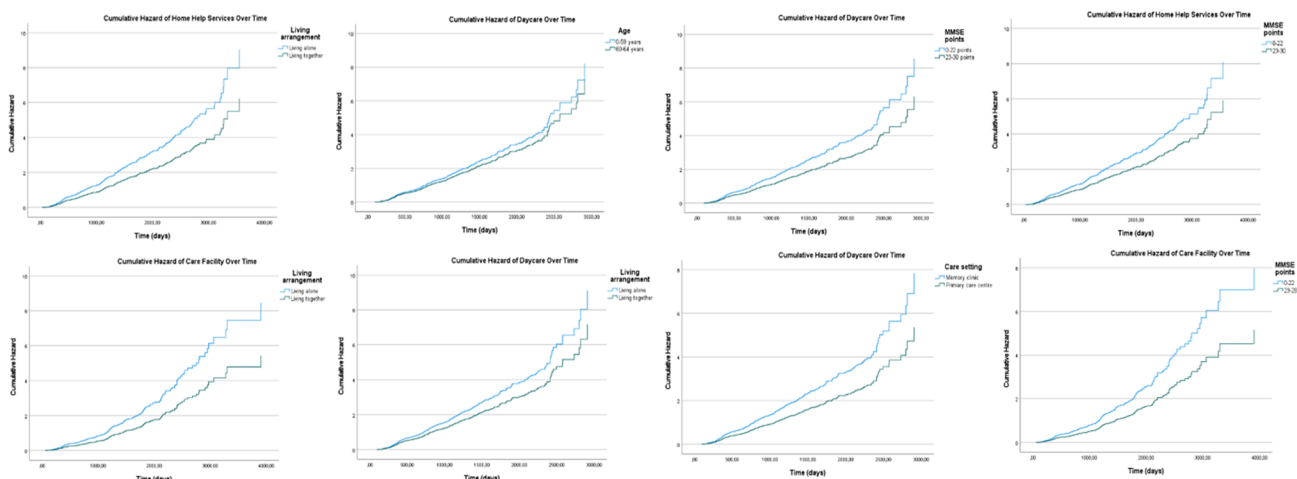


Figure 1. Timing of access to support for persons with young-onset dementia.

for the person with young-onset dementia (Stamou et al., 2021), underscoring the significant time and effort required in informal caregiving roles. Informal caregivers of persons with young-onset dementia often experience considerable strain, which can affect their ability to access and utilise formal support services. Previous research indicates that caregiver burden is linked to earlier institutionalisation for persons with dementia (Afram et al., 2014; Dufournet et al., 2019). Given this context, it is essential to ensure that formal support is available for those living with informal caregivers. Investigating the timing of accessing support services is crucial, particularly to determine if later access to support services conceals a greater caregiver burden. Further research should focus on understanding the time taken to access support services and how it influences caregiver burden for persons with young-onset dementia and their families.

Cognitive functioning significantly influenced the timing of support access. The average MMSE score in the sample was 22.5, below the cut-off score of 24 for cognitive impairment (Folstein et al., 1975). This finding aligns with previous research showing relatively high MMSE scores at diagnosis for persons with young-onset dementia (Chiari et al., 2022; Panegyres, 2021; Wong et al., 2020). National guidelines (National Board of Health and Welfare, 2017) recommend using MMSE as a part of the diagnostic process, and our results indicate high compliance with these guidelines, with approximately 90% of the sample undergoing MMSE testing at diagnosis. Higher MMSE scores were associated with accessing day-care services, home help, and care facilities later than lower MMSE scores. Earlier studies on all-age dementia have shown that higher MMSE at diagnosis are linked to later institutionalisation (Brodaty et al., 2014; Szalontay et al., 2015). Our findings extend this observation to persons with young-onset dementia, suggesting that this observation may also apply to this group. The national dementia guidelines (National Board of Health and Welfare, 2017) recommend providing day-care services to persons with mild to moderate dementia. However, in our sample, persons with higher MMSE scores seemed to access day-care services later than those with lower scores. This pattern may reflect limited availability of age-appropriate services, unrecognised needs within the formal support system, or the possibility that persons with higher cognitive functioning have less need for these services.

Most persons (88.1%) were diagnosed by memory clinics, reflecting the specialised role of these clinics in diagnosing young-onset dementia. Specialised dementia care is associated with better follow-up care, patient satisfaction, and more information and support (Kårelind et al., 2024; Stamou et al., 2021). Garcia-Ptacek et al. (2017) observed that younger persons are less frequently diagnosed in primary care. Similarly, a study from the Netherlands (Hendriks et al., 2023) found that nearly all persons with young-onset dementia (96%) in primary care were referred to a specialist for diagnosis, highlighting the central role of memory clinics as the primary diagnostic facilities for this group. According to our results, persons diagnosed in memory clinics access support services earlier than those in primary care. This could reflect better referral systems or prioritising in memory clinics. Previous research comparing memory clinics and primary care is scarce. Recent research, such as Stamou et al. (2021), focuses on specialised services for young-onset dementia. Our data does not disclose whether the memory clinics offered specialised young-onset dementia care, making comparisons with previous studies difficult. Hence, more in-depth comparisons should be employed to understand how

memory clinics and primary care centres offer prompt support for persons with young-onset dementia.

Age also affected access to support services. Younger persons with young-onset dementia accessed day-care services earlier than older persons with young-onset dementia. This may be due to younger persons experiencing job loss, a common consequence of young-onset dementia, often resulting in a loss of identity, autonomy and purpose (Roach & Drummond, 2014). This disruption in daily life can create unmet needs for daytime activities and social interaction, leaving persons without the structure and engagement that employment once provided (Bakker et al., 2012; Greenwood & Smith, 2016). Sweden's national dementia guidelines recommend offering age-appropriate day-care services, but only 25% of municipalities offer these services (National Board of Health and Welfare, 2017). International studies, such as those from Australia, highlight similar challenges, where lack of age-appropriate services creates barriers to support and contributes to underusing these services (Cations et al., 2017).

The number of medications also did not affect the time needed to obtain any tested support variables. Previous studies have shown that persons with young-onset dementia have a higher prevalence of comorbidities compared to the general population (Carcaillon-Bentata et al., 2021). However, our results showed that comorbidities also did not affect the time to obtain support when using prescribed medications as a proxy for disease, as suggested by Cossman et al. (2010). Sex did not significantly influence the time to access support, which is in line with our previous research, which showed no differences in offered support (Kårelind et al., 2024). However, studies on all-age dementia populations show that women are more likely to be institutionalised than men (Joling et al., 2020; Runte, 2018). Further research is needed to explore whether such disparities exist in young-onset dementia populations.

Limitations

A unique strength of this study lies in the availability of extensive data on persons with young-onset dementia—data that is scarce in most countries. In Sweden, national quality registers such as SveDem provide robust and comprehensive data, offering an in-depth understanding of this otherwise underrepresented population. As a result, the present study is both novel and offers valuable insights in a field where similar studies are rare. Comparing the findings of this study to existing international literature reveals similarities regarding access to support services. However, it is important to acknowledge the challenges in generalising and transferring these findings to countries without similar decentralised healthcare models and welfare systems, such as those in Nordic countries. Therefore, while the results contribute valuable knowledge, their generalisability to other contexts may be limited, and further research is needed to explore how these findings can be adapted to diverse healthcare settings.

Additionally, using quality registry data for research can be challenging, as such registries are mainly designed for internal quality assessments rather than external, detailed research studies. A thorough examination of the registry's operations was conducted to overcome this issue. However, the support variables present in SveDem have limitations. It is unclear from the records whether persons declined support or support was not offered. Additionally, the entries in the registry have mainly binary

(yes/no) responses. This format makes it easier for healthcare professionals to input data as part of their daily routines but limits the information available for research. Moreover, the registry does not collect potential confounders such as socioeconomic status and comorbidities. The absence of these variables introduces the risk of unmeasured confounding, which should be considered when interpreting the findings. These limitations, combined with the dichotomisation of variables for analysis, may oversimplify the data and obscure nuances in the provision and use of support, potentially affecting the accuracy of the findings. In this novel analysis of time to support in a sample of adults with young-onset dementia, the significance level was set to 0.05 to maximise our ability to detect trends in the data. Although a 0.05 significance level may result in an increased Type I error rate, most results were significant at the 0.01 level.

The lack of information regarding the location of the units using the registry could conceal geographical biases that potentially limit the sample's representativeness. The 2021 report by SveDem showed considerable regional differences in baseline entries in the registry (SveDem, 2021). However, the 100% national coverage of memory clinics (SveDem, 2021) enhances representation compared to recruiting a sample with young-onset dementia, where such a large sample would be challenging to obtain. Using registry data also helps collect data about populations usually underrepresented in research (Johansson et al., 2021). Moreover, the focus solely on the perspective of care professionals in SveDem and the absence of self-reported outcome measures have been criticised (Religa et al., 2015). While a self-reported measure regarding support is present in the registry's follow-up module, this variable was recently added (April 2021). As a result, it is not included in our longitudinal dataset.

Conclusions

This study is the first to examine the timing and factors influencing access to formal support services for persons with young-onset dementia in Sweden. Our findings reveal significant differences in access, particularly for persons living with another adult, suggesting a potential caregiver burden. Additionally, the lack of consistent follow-up care highlights the need for improved continuity in service provision. Addressing these gaps requires targeted interventions to ensure timely access and regular follow-ups. Future research should focus on qualitative and longitudinal approaches to better understand how individual, systemic, and geographic factors shape service access. Insights from such research can inform policymakers in developing more effective and equitable support systems for this population.

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Author contributions

FK contributed to data analysis, data curation, and writing, including original draft and editing. DF contributed to study design, data analysis, data curation, writing, reviewing, and editing. LJ contributed to study design, data curation and writing—reviewing and editing. SZ, HW and TB contributed to writing—reviewing and editing. All authors read and approved the final manuscript.

Ethics approval and consent to participate

After an ethical review, the Swedish Ethical Review Authority in Lund approved the current project (DNR: 2022/00459-01). Participants in this study have given their informed consent for their information to be collected by the SveDem Registry and can decline participation or withdraw their information later. However, they are not informed about specific research projects. Researchers have received anonymised data from the SveDem registry, and all data handling and analysis were carried out by relevant ethical guidelines, including those outlined in the Helsinki Declaration.

Disclosure statement

The authors report that there are no competing interests to declare.

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