People living with a dementia diagnosis with no eldercare at all: Who are they?

Atiqur sm-Rahman MCSW, MSS, Lars-Christer Hydén Ph.D, and Susanne Kelfve Ph.D

Abstract

Dementia is a non-curable disease that progressively affects people’s ability to handle their everyday life. Still, previous Swedish research found that many people living with dementia (PlwD) do not use any eldercare. In this study, we investigated the association between not using eldercare services and key social background factors: years with dementia, hospital care, and country of birth for PlwD. We identified all people aged 65+, diagnosed with dementia between January 2006 and March 2015 (n = 43,372) using secondary data analysis of information taken from multiple Swedish nationwide registers. Results showed that not using eldercare was more common among younger age groups and men. The likelihood of having no eldercare was three times higher for those cohabiting; notably, almost a fifth of the PlwD who had the diagnosis for four years or more did not have eldercare at all. Finally, people born outside Europe used eldercare less than persons born in Sweden. Since the public dementia policy in Sweden is basically geared toward PlwD in a later stage and primarily in residential care, there has been almost no policy development around the needs and rights of PlwD in their homes. This study provides a ground for reconsidering dementia policy regardless of the ethnic and cultural backgrounds of PlwD.

Introduction

The number of people living with dementia will increase worldwide during the coming years (Ricci, 2019; WHO, 2020). The main reason for this is that people live longer. Due to the increase in longevity, dementia has become an increasing public health concern in general, but specifically the future use of and demand for care, especially during the last years of life with dementia, is of an even wider concern (Larsson et al., 2014; Prince et al., 2015; Ricci, 2019). Dementia is a disorder that progressively will cause increased cognitive and...
communicative disabilities that generally have severe consequences for the individual’s abilities to perform mundane tasks and to sustain an independent everyday life (Hydén & Antelius, 2017; Livingston et al., 2017). Although many people living with a dementia diagnosis can live on their own in the early phases of the disorder, their care needs increase as the disorder progresses (Abreu et al., 2020; sm-Rahman et al., 2020). During the last phases of the disorder, most individuals will need comprehensive care as they need support to perform basic bodily functions like eating, moving around, as well as personal care (Mlinac & Feng, 2016).

Care for people living with dementia in its different stages is organized in different ways in different countries, ranging from family care to professional care outside the home (Lethin et al., 2018). An international comparative study reported that the percentage of the use of eldercare services among older adults is higher in Denmark (25%) compared to Norway (18%), Canada (17%), and Australia (15%) A country-specific study showed that family members in Germany, Estonia, and Spain are expected to deliver eldercare services, whereas in Sweden and Finland there is no such obligation (Dorin et al., 2014; Leszko & Bugajska, 2015; Lethin et al., 2016). A European cross-country study further found that specialized dementia care and services are sparsely available in Europe in general and that PlwD often received only basic formal care with few adjustments to their specific needs (Bökberg et al., 2015).

In Sweden, eldercare services for older adults are part of a universal welfare system, financed by local taxes, and decided locally by each of the 290 municipalities (Meinow et al., 2020). According to the Social Service Act (2001:453), municipalities are responsible for providing care (e.g., home care, residential care, respite care, and day care) to all citizens who are 65 years and older if their needs cannot be met in any other way (Lethin et al., 2019). It is important to bear in mind that the municipalities have a high degree of freedom, e.g., they decide how they prioritize social care for older people in relation to other municipal responsibilities and to what extent they offer residential care or home care. Although access to services is needs-assessed and not means-tested, there are no national regulations on uniform eligibility criteria. That is, services are available to all citizens regardless of economic situation (Kelfve et al., 2021; Bettina Meinow et al., 2020). Although it has become more common to pay out of pocket for household services as a consequence of tax deductions introduced in 2007, privately purchased help with personal care is still almost nonexistent.

Entering Swedish eldercare system starts with application. Once an application is received, a need assessor deployed by the municipality is legally obliged to evaluate the needs of the applicant. The care manager subsequently assesses the applicant’s needs and offers available services. PlwD are not defined as a special group and are assessed according to the same standards as other eligible persons (Rahman et al., 2021).
The two main forms of eldercare are home care and residential care services. Home care services cover household chores and/or personal care (e.g., help provided with activities of daily living or personal activities of daily living at home by paid professionals), meals on wheels (e.g., a service that delivers cooked meals to older people in their homes), showering, toileting, and help with medication (Odzakovic et al., 2019). On average, a home care user receives around seven hours of help per week (Szebehely & Trydegård, 2012), but the intensity varies greatly, going from one or two hours a month to several times a day and night. Besides that, several additional services are available, e.g., day care (mostly for people with dementia), short-term residential care where the older person is cared for in a residential care facility for a shorter time period, one-time (e.g., after discharge from hospital) or on a regular basis as respite care. Assistive technology, for example, safety alarms, walking aids, etc., are also available (Peterson, 2017). Depending on individual needs, home care services can be offered around the clock and may be complemented with primary care providing nursing care in the homes.

Residential care, also known as “special housing,” refers to institutional care in a long-term residential setting (Corneliussen et al., 2019). It covers nursing home care (e.g., medical needs, dementia care, and terminal illness), sheltered accommodation or group accommodation for people with dementia (Spangler et al., 2019). Most people enter the eldercare system through home care, and residential care is only approved if (an increase in) home care is considered to be insufficient (Johansson & Schön, 2017). Since the number of beds in residential care have decreased drastically during the past two decades, eligibility thresholds for access have risen (Schön et al., 2016). Admission to residential care in general requires need for around-the-clock care and/or supervision and a majority of those living in residential care has major cognitive impairments (Meinow et al., 2020bb).

A number of factors influence the kind of care that is available, optional, and utilized, from cultural and social traditions to economic resources. Professional care is obviously dependent on economic resources being available both for its organization and utilization. This makes Scandinavian countries interesting because in these countries, dementia care is part of eldercare, which is publicly organized and funded. Dementia care as well as eldercare are available for all citizens either for free or for a low cost after a need assessment from a social worker. Thus, it could be expected that all people living with dementia and their relatives and their close networks in these countries, make use of the public system of eldercare in order to make a good life possible for persons living with dementia and their relatives. (In this study, when we use the word eldercare, we are referring to both home care and residential care services.)

From previous research, we know that in Sweden, nearly 60% of people living with a dementia diagnosis are living at home, while 42% live in
residential care facilities (Rahman et al., 2021; Religa et al., 2015). Further, about half of all persons with a dementia diagnosis living in the community have no elderscare at all (Odzakovic et al., 2019; Wimo et al., 2016). These studies found that a fairly large group of people living with a dementia diagnosis did not use home care (personal assistance like help getting out of bed, dressing, or help with domestic chores or assistive technology-like safety alarms), or residential care (nursing home or special housing; Corneliusson et al., 2019). This is somewhat surprising given that the significant literature about the effects of dementia on the ability to manage activities of daily life (ADL), communication, and to live independently with optimum capabilities of cognitive functionalities (Poulos et al., 2017; Taylor et al., 2018; Wallcook et al., 2019).

In this study, the aim is to explore and investigate people in the age group 65+ living with a dementia diagnosis in Sweden, who do not utilize any elderscare (home care or residential care) and what key social background factors are associated with not using elderscare. More specifically, three research questions are posed:

(i) What are the differences between those persons with a dementia diagnosis who receive elderscare compared to those with no elderscare?
(ii) How does the relationship between the likelihood of having no elderscare and number of years with a dementia diagnosis look like, and does this association differ by age and gender?
(iii) To what extent are sociodemographic factors (gender, age, level of education, cohabitation status, and type of municipality), years with the dementia diagnosis, and health (measured by hospital nights) associated with having no elderscare among people living with dementia?

Methods

Data sources

Data were derived from individually linked Swedish registers with national coverage. Sociodemographic factors were collected from the LISA database – a longitudinal register of all inhabitants in Sweden, and level of education comes from the National Register of Education, both administered by Statistic Sweden. The date of death comes from the National Cause of Death Register and the date of the dementia diagnosis, as well as the number of nights in hospital, were extracted from the National Patient Registers (in-patient care as well as specialist care), all administered by the Swedish National Board of Health and Welfare. Information about elderscare comes from the Social Service Register, a register also administered by the National Board of
Health and Welfare, gathering, and providing monthly information from all municipalities regarding their decisions about eldercare.

**Study sample**

The study sample consist of all individuals aged 65 and older living in Sweden in 2014 and still alive on the 31st of March 2015 who have been diagnosed at a hospital clinic with a dementia diagnosis (ICD10-codes F00-F03 or G30-G32) any time between 1st of January 2006 and 31st of March 2015, comprising a total study sample of 43,372 individuals.

**Outcome variable**

Our outcome of interest was “have or do not have eldercare services,” measured by receiving or not receiving any type of formal eldercare services during March 2015, according to the Social Service Register.

**Predictors**

*Years with dementia diagnosis* were measured up until 2015—the year of the first dementia diagnosis was recorded in the National Patient Registers, coded into 0–1, 2, 3, 4, 5, and 6+ years. *Age* was measured by 2015-birth year, coded into seven age groups (65 to 69 years, 70 to 74 years, 75 to 79 years, 80 to 85 years, 86 to 89 years, 90 to 95 years, and 95+ years) or three age groups (65–74 years, 75–84 years, 85+ years). *Days in hospital* was measured as number of hospital nights during the last 12 months, here, used as a proxy for health (Karlsson et al., 2015), calculated in 1st of March 2014, and were grouped as <1 day, 1 to 5 days, 6 to 10 days, 11 to 30 days, 31 to 60 days, and 61 to 365 days. The *highest level of education* was categorized into compulsory, upper secondary, and tertiary education. People with missing information on education (n = 887) were considered in a separate category. This incomplete or missing data on education has no bias on speculation about the eldercare usage. We also considered *cohabitation status*, classified as cohabiting (married or share household) or living alone, and *type of municipality*, characterized as urban, semi-urban, and rural, in December 2014. *Country of birth* was determined by the birthplace of the person and grouped into people who born in Sweden, any other Nordic country, anywhere in Europe, and outside of Europe.

**Statistical analysis**

This study carried out a secondary data analysis of information taken from various Swedish national registry databases. First, we performed descriptive
analyses for all predictors as percentages of people with and without eldercare services. Age and years with dementia diagnosis were also presented with means and standard deviations. Second, we compared mean years of dementia diagnosis among people with and without eldercare, as well as the proportion of people without eldercare by years with dementia diagnosis, for men and women in different age groups.

Finally, we estimated odds ratios of not having any eldercare services for all predictors using logistic regression, both bivariate and adjusted for all predictors. All statistical analyses were performed in STATA 14 (StataCorp, College Station, TX).

**Results**

In total, roughly a quarter of all persons living with a dementia diagnosis did not have any eldercare (24%). The socio-demographic characteristics and the use of eldercare services among the study population are presented in Table 1. The mean age of those who did not have an eldercare was 77.5 years (SD = 6.9), while the mean age for those who did use eldercare was slightly higher (83.3; SD = 7.2). The proportion of persons with no eldercare services was higher for men (30%) than women (19%). In the younger age group (e.g., 65–69 years, 51%), a higher proportion were more likely to not have any eldercare compared to the older age group (e.g., 90–94 years, 7%). At the age of 74–79 years old, nearly a third of persons living with dementia had no eldercare services. The majority of the study population was born in Sweden (86.9%) and having no eldercare was more common among people with a dementia diagnosis born outside Sweden, in particular, outside of Europe.

Among person who were cohabiting, 40% did not have any eldercare, while only 13% among those who lived alone did not have any eldercare. Among people with higher education, 29% have no eldercare compared to those with compulsory and secondary education (20% and 25%). No notable differences could be identified in the proportion of people with no eldercare between those living in urban (23%), semi-urban (24%) or rural (23%) municipalities.

In the total population, the mean years with dementia diagnosis was 3.5 years (SD = 2.5). Table 1 further shows that approximately 30% of the people newly diagnosed with dementia (0–1 year) had no eldercare service, while among those who had lived with a dementia diagnosis for six years and more, 18% had no eldercare. Among the persons who had spent no time during the previous year in hospitals a quarter had no eldercare at all, whilst it was less common among those who spent more days in hospital.

To further understand the association between the use of eldercare and the number of years with a dementia diagnosis, the use of eldercare among men and women in different age groups was analyzed (Table 2). Among people with no eldercare – in all age groups and both among men and women – the
mean number of years living with dementia were slightly lower compared to people with eldercare. Three things are notable concerning the connection between having no eldercare and time with a dementia diagnosis. First, the longer time spent with a dementia diagnosis, the lower the probability of not having any eldercare. However, this association is quite moderate. For example, the differences among men newly diagnosed with dementia and men that had the diagnosis for at least six years were 38% compared to 25%. Corresponding numbers
Table 2. Mean years of dementia diagnosis among people with eldercare and with no eldercare by age group and gender and proportion of people with no eldercare by years with dementia diagnosis, age group, and gender.

|                     | 65–74 years | 75–84 years | 85+ years | Total |
|---------------------|-------------|-------------|-----------|-------|
|                     | Men         | Women       | Men       | Women  | Men     | Women    |
| People without eldercare |             |             |           |        |         |          |
| Mean (SD)            | 3.2 (2.6)   | 3.1 (2.5)   | 2.8 (2.3) | 2.9 (2.3) | 3.1 (2.5) | 3.2 (2.5) | 3.0 (2.5) | 3.0 (2.4) |
| n                   | 1791        | 1725        | 2617      | 2336   | 816     | 918      | 5224      | 4979   |
| People with eldercare |             |             |           |        |         |          |
| Mean (SD)            | 3.7 (2.5)   | 3.9 (2.5)   | 3.5 (2.4) | 3.7 (2.5) | 3.5 (2.5) | 3.8 (2.6) | 3.6 (2.5) | 3.8 (2.5) |
| n                   | 2106        | 2298        | 5381      | 7933   | 4561    | 10,890   | 12,048    | 21,121 |

Percentage of people without eldercare

| Years with dementia diagnosis | 0–1 years | 2 | 3 | 4 | 5 | 6+ years | Total |
|-------------------------------|-----------|---|---|---|---|----------|-------|
| %                             | %         | % | % | % | % | %        | %     |
| People without eldercare      |           |   |   |   |   |          |       |
| Percentage                   | 56.6      | 56.3 | 42.6 | 30.9 | 18.0 | 10.1 | 38.5 | 26.1 |
| Years with dementia diagnosis | 0–1 years | 2 | 3 | 4 | 5 | 6+ years | Total |
| %                             | %         | % | % | % | % | % | % | % |
| People without eldercare      |           |   |   |   |   |          |       |
| Percentage                   | 56.6      | 56.3 | 42.6 | 30.9 | 18.0 | 10.1 | 38.5 | 26.1 |

among women are 26% compared to 14%. Second, more notable is the association between age and the likelihood of not having eldercare. In the youngest age group, 56% of men and women with a new diagnosis had no eldercare, while the corresponding number among people 85 years and older were 18% of men and 10% of women. Third, we found a considerable age and gender interaction effect, where a similar percentage of men and women in the youngest age group had no eldercare, while the gender differences in the older age groups were much more profound: having no eldercare was more common among men.

Logistic regression models were performed to model how sociodemographic factors, years with a dementia diagnosis, number of hospital nights, and country of birth predict no use of eldercare services among PlwD (Table 3). In line with the descriptive results from Table 1, the bivariate regression models showed that women compared to men and older age groups compared with younger age groups had lower odds of no eldercare. People who had more years with a dementia diagnosis and spent more nights in hospital were associated with lower odds of no eldercare. On the contrary, higher odds of no eldercare were observed among people who are cohabiting as well as among those with a higher level of education. No major educational differences were found in the adjusted results. Notable is that also those with missing information on education had higher odds for no eldercare compared with people with compulsory education.

The bivariate regression models further confirmed a weak association between the odds of no eldercare and type of municipality, where those living
in semi-urban areas had slightly higher odds (OR = 1.07; p-value = 0.015) compared to those living in urban areas, while no statistically significant difference was found between people in rural and urban areas.

Finally, we found a strong association between the odds of having no eldercare and country of birth. In general, all people born outside of Sweden have higher odds of not having any eldercare compared to those born in Sweden. Having no eldercare was significantly higher among people born in Europe (OR = 1.61; p-value = <0.001) or outside of Europe (OR = 1.30; p-value = <0.001) compared to people born in Nordic countries.
After adjustment, that is, including all predictors in the same model, the results show small differences compared with the bivariate associations for most of the variables. The main differences are that the odds ratios for women changed from 0.54 (p-value < 0.001) to 0.84 (p-value < 0.001), indicating that the lower odds of having no eldercare for women with dementia, compared to men with dementia, can partly be explained by differences between men and women regarding other sociodemographic factors, health, or years with dementia. Adjusting for the other predictors also changed the association between the type of municipality and the odds of having no eldercare. In the adjusted model, people living in both semi-urban (OR = 0.93; p-value = 0.020) and in particular rural areas (OR = 0.87; p-value < 0.001) showed lower odds of not having any eldercare.

Discussion

Based on multiple Swedish registers with national coverage, the focus of this article was on PlwD who do not have eldercare. We examined how different social demographic factors, health (measured by hospital nights), and years with dementia were associated with no eldercare use. In the following, we first want to discuss the sociodemographic aspects of people living with dementia who do not use any eldercare. Second, we want to discuss a number of possible explanations for this fact.

We found that about a fourth of all persons living with a dementia diagnosis did not have or use any eldercare service. This is consistent with previous findings (Odzakovic et al., 2019; Wimo et al., 2016). At the same time, the finding is surprising because dementia is a disorder that causes cognitive and communicative disabilities that makes it very difficult for persons with dementia to pursue the activities of daily living on their own. Looking further into sociodemographics of the persons having no eldercare shows that age, gender, cohabitation, and time with a dementia diagnosis are important in understanding which persons with dementia that did not have or use any eldercare.

First, it is clear that age is a strong predictor for not having any eldercare – older persons are more likely to use eldercare compared to younger. The majority of persons with dementia who do not use eldercare belong to the relatively younger group, which corresponds to previous research (Kerpershoek et al., 2020). The remarkable point in our finding on the age effect is that quite a few persons living with dementia did not receive any eldercare until the age of 79 years. As far as we know, this finding represented new knowledge. We found a similar age effect in a previous study where older adults with and without a dementia diagnosis were in focus (Rahman et al., 2021).

Second, gender has a significant correlation with having no eldercare – men tend not to use eldercare while women more often do. The finding in this
study, that men more commonly do not make use of eldercare, corresponds to the findings in a number of studies that women with dementia have more eldercare than men (Dahlberg et al., 2018; Gruneir et al., 2013). It is possible that this is explained by higher life expectancy among women. Higher life expectancy among women was controlled for the present analysis but results still indicated a significantly higher proportion of men than women who have no eldercare. One possible reason for this might be that more women than men provide care for their partner with dementia living at home (Lethin et al., 2019; Levesque et al., 2013).

Third, there is a relationship between cohabiting status and having no eldercare – people cohabiting are more likely to not use eldercare. Previous Swedish studies have found that the use of eldercare was less among cohabiting or married older adults than among those who were living alone (Larsson et al., 2014; Odzakovic et al., 2019). In our study, we found similar results for persons living with dementia. The likelihood of no eldercare was three times higher for those living with a spouse or a partner. The result might thus indicate access to informal care provided by family members, next-to-kin, or friends, that is supported by a recent study that found that spouses and adult children are the main sources of informal care for cohabiting people with dementia living at home (Lethin et al., 2019).

Fourth and finally, years with dementia diagnosis played a crucial role in relation to no eldercare – people who received a diagnosis recently tend to use eldercare less compared to person who had a dementia diagnosis for many years. The likelihood of no eldercare decreased with the number of years with a dementia diagnosis. This finding corresponds with an earlier study where extensive care needs were found for the person with dementia at their late stages (Lethin et al., 2018). Even though the likelihood of not having eldercare of both genders was more common among younger and newly diagnosed individuals, more men than women in older age groups with longer dementia had no eldercare. It can also be noted that almost a fifth of the persons who had a dementia diagnosis for four years or more did not have any eldercare.

Given this analysis, what are the possible explanations for the fact that a quarter of all persons with dementia diagnosis in Sweden do not have any eldercare? A first possible explanation is, of course, that this group of people do not experience that they need any eldercare and thus do not apply for eldercare. The persons without eldercare are younger and have received their diagnosis more recently and are thus in the early phases of the disorder and are most probably able to pursue the necessary daily activities on their own, in their own home.

This explanation can be combined with a second supportive explanation: the existence of family support at home. For example, if a person with a dementia diagnosis has support from, for instance, a spouse in their home, they can pursue their lives without eldercare, although with some reservations. From previous
research, it is known that family support often translates into a functioning spouse or a family network, often consisting of women (Chiatti et al., 2018; Farina et al., 2017; Giertz et al., 2019). Following our data, support provided by the spouse or family seems to be sufficient, at least at the beginning of the dementia disorder and as the person with dementia is relatively younger. With advancing age, the likelihood that the spouse either becomes sick and thus unable to provide support or actually dies, increases, and the person with dementia needs to use eldercare services provided by the municipality.

A third explanation of the fact that a quarter of all persons living with dementia do not have any eldercare, might be that the municipal eldercare has not been able to reach all persons that actually needs eldercare support with information about eldercare support or their information not being persuasive enough. Persons will get their dementia diagnosis from the health care, either from a general practitioner (GP) or preferable from a geriatrician at a memory clinic (Socialstyrelsen, 2016). In Sweden, health care is totally separate from the eldercare, and information from the healthcare is not likely to reach the eldercare. Although the health-care provider always provides a person who receives a dementia diagnosis with information about the possibilities of eldercare, it might happen that this information gets lost in the process of receiving the dementia diagnosis. In particular, if support from a spouse or other family members is not present.

A fourth explanation might be a missing fit between the kind of support that is provided by municipal eldercare and what the person with dementia (and his or her social network) would like to have support with. That is, the eldercare may provide support, but not the kind of support people with dementia need. Much of the eldercare services provided by the municipality are geared toward people primarily needing support for their ADL rather than at the specific needs generated by dementia disorder. This explanation is supported by the fact that there is a strong association between the number of hospital nights and having eldercare, while the association between numbers of years with a dementia diagnosis and receiving eldercare service is less strong. Although PlwD diagnosis need support for activities of daily living, they also have specific needs as a result of the dementia disorder (Bökberg et al., 2015).

More specifically, besides creating needs for support of activities of daily life, dementia also entails a number of specific challenges: with planning, organization and performing everyday life, communication and social interaction, as well as keeping up with social relations (Hydén & Antelius, 2017). Thus, persons living with a dementia diagnosis not only need support around personal hygiene and eating, but also with organizing and performing all aspects of everyday life (Hydén, 2014). This in turn presupposes services that are geared toward these specific needs as well as eldercare staff with an educational background for working with PlwD. This is often not the case in eldercare.
Finally, a fifth explanation might have to do with cultural traditions among immigrants. As almost a fifth of all persons over 65 years of age living in Sweden are born outside Sweden (Swedish Institute, 2021) it is likely that at least large groups among the immigrant may have other traditions and preferences regarding care of elderly family members with dementia (Antelius, 2017). In many cultures, the preference is for the family to care for family members with dementia. The utilization of formal professional care such as the one provided by the municipality is seen as abandoning the filial and moral obligations of the children toward their elderly parents with dementia. As a consequence, families from cultures with a family care preference, do not apply for and do not use municipal eldercare.

**Strengths and limitations**

A main strength of this study was the use of data from multiple national Swedish registers. Although the Swedish national health-care register is reliable in detecting dementia cases due to its high quality, completeness, and long history (Brooke et al., 2017; Rizzuto et al., 2018) some information about individuals living with a dementia diagnosis might be missing. Thus, a main limitation of this study is that we only have data about dementia diagnosis provided by hospital clinics but not about dementia diagnosis provided by General Practitioners in health-care centers (Vårdcentraler). At the same time, the preferred diagnostic procedure recommended by the National Board of Health is based on the services provided by hospital clinics. A second group that might be missing from the health-care register are older persons in residential care and who develop dementia but do not receive a dementia diagnosis. We also acknowledge that the dataset we used for this study does not consist of data about the care giving process (e.g., spousal, family) and the coping strategy of PlwD who did not have any eldercare. Thus, it was not possible in this study to speculate on any outcome related to caregiving or coping mechanisms of PlwD with no eldercare.

**Conclusions**

In conclusion, this study provides unique insight into the fact that, surprisingly, many older Swedish adults who live with a dementia diagnosis do not receive any eldercare services. Our study suggests that it is important to develop exploratory research on people who are diagnosed with dementia but without any eldercare at all in order to better understand what specific care needs PlwD have in relation to the services today available from the municipal eldercare. In particular, it is important to investigate if there is a need to expand the kind of services provided by eldercare for a better fit with what people living with dementia need. It is also important to make sure that
information about eldercare is provided to all persons who receive a dementia diagnosis. It is also important to better understand how to provide eldercare services to immigrants living with dementia. Finally, we think that this study provides ground for reconsidering dementia policy. In Sweden, the public dementia policy is basically geared toward people living with dementia at later stages and primarily in residential care. There has been almost no policy development around the needs and rights for people living with dementia in their homes – and without any eldercare at all. As this study shows, the proportion of people living at home without eldercare is substantial, and most probably could benefit from various forms of support in terms of for instance, “dementia friendly neighborhoods” (Keady et al., 2012; Odzakovic et al., 2020) or cities (Buckner et al., 2019; Gaber et al., 2020), as well as possibilities for participation in the local community (Nedlund & Nordh, 2015).

Key points

- About a fourth of all persons living with a dementia diagnosis do not have or use any eldercare service in Sweden.
- Age and gender have a significant correlation with having no eldercare for people living with dementia.
- The likelihood of having no eldercare is three times higher for those living with a spouse or a partner compared to those living alone.
- Years with dementia diagnosis play a crucial role in relation to having no eldercare, and almost a fifth of the persons who had a dementia diagnosis for four years or more did not have any eldercare.
- Country of birth is a strong predictor: people who are born outside Europe used less eldercare compared to the persons born in Sweden.

Disclosure statement

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ORCID

Atiqur sm-Rahman MCSW, MSS http://orcid.org/0000-0002-7675-2415
Lars-Christer Hydén Ph.D http://orcid.org/0000-0002-3033-9879
Susanne Kelfve Ph.D http://orcid.org/0000-0001-9369-1928
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