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# The societal costs of dementia in Sweden 2012 – relevance and methodological challenges in valuing informal care

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## Abstract

**Background:** In this study, we sought to estimate the societal cost of illness in dementia in Sweden in 2012 using different costing approaches to highlight methodological issues.

**Methods:** We conducted a prevalence-based cost-of-illness study with a societal perspective.

**Results:** The societal costs of dementia in Sweden in 2012 were SEK 62.9 billion (approximately €7.2 billion, approximately US\$9.0 billion) or SEK 398,000 per person with dementia (approximately €45,000, approximately US\$57,000). By far the most important cost item is the cost of institutional care: about 60% of the costs. In the sensitivity analysis, different quantification and costing approaches for informal care resulted in a great variation in the total societal cost, ranging from SEK 60 billion (€6.8 billion, US\$8.6 billion) to SEK 124 billion (€14.1 billion, US\$17.8 billion).

**Conclusions:** The societal costs of dementia are very high. The cost per person with dementia has decreased somewhat, mainly because of de-institutionalisation. The majority of the costs occur in the social care sector, but the costing of informal care is crucial for the cost estimates.

**Keywords:** Costing study, Cost of illness, Dementia, Alzheimer's disease, Sweden

## Background

Dementia disorders are chronic, long-lasting diseases that impair cognition, social capacity and daily functioning of the persons affected. As a consequence, dementia heavily influences the situation not only for the patients themselves but also for family members and other next of kin. Furthermore, dementia disorders are also very resource-demanding and costly, which, in a setting of scarce public resources and, in many countries, ongoing changes in care systems, puts great stress on decision makers and budget holders. The worldwide societal cost of dementia care was estimated to be US\$604 billion for

36 million persons with dementia (PWD) in 2010 [1, 2]. The magnitude and allocation of resource use and costs are of interest when present and future care is discussed in terms of organisation, volume and financing.

The situation in dementia care is dynamic. Demographic prognoses predict a rapid increase in the number of people affected [3–5], making the situation even more urgent, and apocalyptic scenarios of the 'dementia bomb' and suchlike have been presented [6]. In contrast, some studies have indicated that age-specific incidence and/or prevalence of dementia and cognitive impairment might have decreased in high-income countries such as the United States, the United Kingdom, The Netherlands and Sweden [7–11]. Symptomatic drug treatment for Alzheimer's disease has been available for almost 20 years. Studies on potential disease-modifying agents have so far not been successful, although there are still many compounds in clinical development [12, 13]. Because of changes in long-term care policies, as well

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as strategies and pressures for cost containment in health care and social care systems, there is a trend towards de-institutionalisation in some countries [14].

In 1991, the cost of illness (COI) in Sweden was estimated to be 31 billion Swedish krona (SEK) for a dementia population of 154,000 (which is probably an overestimate of the prevalence) [15]. For 2000, the cost was estimated to be SEK 38 billion for 133,000 PWD [16], and for 2005, it was estimated as SEK 50 billion for 142,000 PWD [17]. There is also a wide range in estimates of COI for dementia in other countries [18]. Of course, there are true differences in the COI of dementia, but the variability in COI figures could also be the result of methodological issues, such as prevalence sources, whether costs of informal care are included and how care is quantified and costed or whether clinical/convenience samples or population-based studies are used as sources for the cost estimates.

The purpose of this paper was to estimate the societal COI of dementia in Sweden in 2012, using different approaches to highlight methodological issues. We also aimed to compare the time trend in COI from 2000 to 2012 when using similar methods. This paper is based on a report that was commissioned by the Swedish National Board of Health and Welfare (NBHW) [19].

## Methods

### COI approach

COI studies can be prevalence- or incidence-based [20]. If the aim is to estimate the economic burden during a certain time period, the prevalence approach is recommended; however, if the aim is to illustrate the economic consequences of policy change (e.g., prevention, treatment, changes in care organisation), the incidence approach may be preferred [21]. Another issue is whether a bottom-up or top-down approach is to be used (or a combination of the two). In a bottom-up study, resource use and costs of a defined (often local) population are described in detail, and, in a step 2, results are extrapolated to a much larger population, such as all persons with the disease in a country. Such results can be based on cross-sectional point estimates or on longitudinal data. Study populations in bottom-up studies can be population-based or be derived from other kinds of study populations (e.g., clinic/hospital-based, convenience samples). In top-down studies, the share of total resource use and cost of care in the region that is attributable to the disease of interest are calculated, often using data from registers and other databases. A combination of the two approaches may also be required, depending on data availability. The distinction between costs for patients with a certain disease ('gross costs') and costs due to the disease ('net costs') is important; attributability of costs to a specific condition cannot be observed directly, but can only

be inferred (e.g., by comparing with costs for subjects without the condition).

The perspective of a COI study defines the viewpoint of the calculations. The societal perspective includes all costs, regardless of the payer, and is recommended by most published guidelines for economic evaluations [22]. In the case of dementia, this means that informal care is assigned a cost. The viewpoint can also be narrowed down, such as a county council, a municipality, an insurance company or a health maintenance organisation.

Costs are often divided into direct costs ('costs of resources used' for medical and social/non-medical care) and indirect costs ('costs of resources lost' due to production losses because of morbidity and mortality). Informal care by non-professionals such as next of kin may be difficult to classify in these terms. If the informal carers are being remunerated to some extent, it may be regarded as a direct cost, though this often applies to only a low proportion of the total caregiving time. If the carer has partly given up work to care for the PWD, this constitutes an indirect cost equal to the value of the lost productivity. Informal care by retired persons or care during 'non-working' time is more complicated to evaluate and assign an opportunity cost, because there is no market for this resource.

In this paper, we apply several methodological approaches. We use a prevalence-based societal perspective in which both bottom-up and top-down methods are employed, and we also present estimates of both gross and net costs.

### Epidemiology

In a prevalence-based COI study, the number of persons with the disease in question is essential. Because individual diagnoses of all PWD are not available, estimates of the number of PWD are necessary. Such estimates are based on demographic statistics (from Statistics Sweden in this paper) and age-specific dementia prevalence figures (e.g., in 5-year classes). In this paper, we use such meta-analysis-based figures presented by the Swedish Agency for Health Technology Assessment (SBU) [23]: 1% for persons aged 60–64 years, 1.5% for 65–69 years, 3% for 70–74 years, 6% for 75–79 years, 13% for 80–84 years, 24% for 85–89 years, 34% for 90–94 years and 45% for 95 years and older. Because there is a discussion currently regarding age-specific dementia prevalence [10], we also present results based on other prevalence sources [3, 8, 9, 24–28] in the sensitivity analysis. In the base option, we assume that in 2012 there were 158,000 PWD in Sweden. The number of incident cases of dementia in Sweden in 2012 (based on demographic statistics and adjusted for prevalent dementia cases) and the meta-analysis by Fratiglioni et al. [29] is estimated at 25,000 persons.

### Care organisation in Sweden

PWD in Sweden receive care using several care alternatives. Basically, health care is provided by doctors, registered and enrolled nurses, occupational therapists and physiotherapists, in the own homes of the elderly, in an institution or in hospitals. The municipality's social services offer home help, such as help with daily activities (shopping, cooking, cleaning and laundry and/or personal care such as help with feeding, bathing, toileting, getting [un]dressed and into/out of bed). There is also a range of other services, such as home nursing, transportation services, day care, short-term institutional care, meals on wheels, security alarms, housing adaptations and technical aids. A varying amount of informal care is also common at home. (There is also a small amount of informal care in institutions [30].)

Medical direct costs include costs of hospital care, physician clinic visits, physician visits in primary care, visits to emergency units without hospitalisation, visits to and by rehabilitation staff, drug costs and costs of diagnoses. Non-medical direct costs include costs of institutional care, day care and social services. In this paper, indirect costs are restricted to production losses for patients.

To distribute the Swedish population of PWD (158,000 persons) in the care system for the elderly in 2012, we use a combination of results from bottom-up figures, mainly from population-based projects such as the Kungsholmen project [30, 31] and the Swedish National Study on Aging and Care (SNAC) [32, 33], as well as national top-down data [34–38]. Institutional care is divided into three types: nursing homes, group living for PWD and 'other' types of sheltered housing (e.g., different types of residential care facilities) [16]. On the basis of population-based studies, 58% of PWD were assumed to live at home and 42% in different kinds of institutional care at various proportions (40–100%) (Table 1).

**Table 1** Estimated distribution of the Swedish population with dementia in the care system in 2012

|                                 | %   | Proportion of PWD (%) | Number of PWD |
|---------------------------------|-----|-----------------------|---------------|
| At home                         | 58  |                       | 91,900        |
| Of those with respite care      |     |                       | 3900          |
| Institution                     | 42  |                       | 66,100        |
| All institutional care          |     |                       |               |
| Higher staffed                  | 75  |                       | 19,000        |
| Group living                    | 100 |                       | 30,000        |
| Lower staffed                   | 40  |                       | 14,000        |
| Institutionalised <65 years old |     |                       | 3100          |
| All                             |     |                       | 158,000       |

PWD Persons with dementia

### Resource use and costs

The list of potential resources that PWD might use is large, and it is necessary to focus on resource items that are significant cost drivers. All costs are expressed as 2012 SEK (1 € = SEK 8.77, 1 US\$ = SEK 6.96).

#### Direct costs

**Social care sector** Care for PWD in the social care sector consists of support at home by home help, day care, respite care and long-term institutional care.

**Home care** About 92,000 PWD are estimated to be living at home. For the quantification of support at home, we used the approach of the Resource Utilization in Dementia (RUD) instrument [39], where formal (and informal) care is divided into three proportions: support in personal/basic activities of daily living (PADL), instrumental activities of daily living (IADL) and supervision. For home help services, we used figures based on PADL and IADL. On the basis of Swedish studies where the RUD instrument has been used [40, 41], we estimated the average daily support at 0.5 h/day. This average figure also includes zero users. The hourly cost for formal home care is derived from the Swedish Association of Local Authorities and Regions (SALAR) [42].

**Day care** The Swedish Dementia Registry (SveDem) was established in 2007. It is an Internet-based quality register where several indicators can be followed over time according to national guidelines, such as diagnostic workup, medical treatment and support from community [43]. On the basis of extrapolations from the annual reports from SveDem [44] (adjusted for incomplete coverage), we estimate that 10,000 PWD have access to day care every year. The annual unit cost for day care is derived from statistics from the NBHW [45].

**Institutional care** The method of classifying institutional care in Sweden has changed over the years. In a report for the NBHW regarding staffing of long-term institutional care, three levels were used: living in facilities purposely designed for people with dementia (group living, collective living, group dwelling) [36], high-staffed (e.g., nursing homes) and low-staffed (residential care facilities). Table 1 displays the distribution and proportions of PWD in the different forms of institutional care, based on updates of the previous COI estimates [16, 17] and calculations in the Swedish national dementia guidelines [46]. There are also small numbers of PWD younger than 65 years of age as well as PWD using short-term respite care embedded in institutional facilities (annualised rate).

**Dementia nurse** An expanding and valuable resource in dementia care is the dementia nurse, who organises

support for families, coordinates care and also works with overall planning of dementia care. It is estimated that there were about 500 such nurses in 2012 [47]. As unit cost for the dementia nurses, we used the average monthly salary for specially trained nurses, including the social security charges [48].

**Medical care sector costs** Care for PWD in the medical care sector consists of hospital care, visits to primary care, visits to various specialist clinics (including some of the costs for diagnostic procedures), visits to emergency rooms, use of rehabilitation resources and drug use. The unit costs for these resources are derived mainly from the costing database from SALAR [49].

**Hospital care** Figures regarding the use of hospital inpatient care are derived from the Swedish National Patient Register for the diagnoses F000, F001, F002, F009, F012, F020, F021, F022, F023, F028, G300, G301, G308 and G309 [50].

**Outpatient care visits** Similarly to the figures for inpatient hospital care, visits to specialists were derived from the National Patient Register [50]. Regarding other outpatient care visits (e.g., primary care, occupational therapists, physiotherapists), there is no national statistical source available. However, on the basis of data from the SNAC project [51–53], it was estimated that PWD made two visits per year to family physicians and four visits each per year to district nurses, occupational therapists and physiotherapists.

**Diagnosis** On the basis of an inquiry by the Swedish Ministry of Health to specialist clinics, it was estimated that there were 14,000 diagnostic workups per year in 2003 [34]. In the SveDem register, about 4000 newly diagnosed PWD are registered every year [44]. According to a recent questionnaire sent from SveDem to the memory clinics in Sweden, about 50% of those who went through the diagnostic workup got a final dementia diagnosis. Because the register does not have a completely nationwide coverage, we assume that there still are 14,000 diagnostic workups in specialist care. The figures for primary health care are more difficult to estimate. In SveDem, about 3500 newly diagnosed PWD are registered in primary care. About two-thirds of the primary care centres are part of SveDem, and, given the assumption that 50% also get a dementia diagnosis in primary care, we assume that there are about 10,000 diagnostic procedures in primary care every year. In a paper from SveDem, the costs for diagnostic workup were estimated to be SEK 7017 in primary care and SEK 12,095 on the specialist level. These cost figures are in

line with those reported in another Swedish paper from the Kalmar region of Sweden [54].

**Drug use** The Nordanstig and Kungsholmen SNAC sites in Stockholm include individual and diagnosis-related (e.g., dementia) information about drug use and its related costs [55].

**Informal care** Quantification and costing of informal care and unpaid work are controversial and complicated issues [56–58]. It is challenging to delimit time spent by caregivers on different caregiving tasks (e.g., supervision) and to determine whether each activity has an opportunity cost (i.e., what is the value of the caregiver's time in its best alternative use). We relied on several previous studies in which researchers used the RUD framework to estimate caregiving time [39]. To avoid overestimates of informal care, we aimed to use population-based data wherever possible. One such source is the Nordanstig project [40], and now we can also add data regarding the amount of informal care from the database in the SNAC project (baseline 2001–2003 and follow-up 2007–2009). On the basis of information from these sources, we estimate that PWD receive a daily support of 1.9 h in PADL and IADL. We also have data from other Swedish studies on informal care with the RUD instrument [41, 59, 60]. In these studies, the range was 1.5–3.3 h per day in PADL and IADL support. These figures, as well as data on supervision needs, are used in the sensitivity analysis. Several costing approaches have been discussed [56, 61–64]. In theory, informal care should be valued by the opportunity cost of the carers' time. However, identifying this opportunity cost is not straightforward [65]. Market prices are not available, except for carers of working age, and, in many cases, it is not apparent what the 'best alternative use' of the carers' time is. The main providers of informal care are spouses and the children/children's spouses of the PWD. Thus, in the base case, the cost of informal care is weighted and based on studies where the proportion of spouses (two-thirds) and children (one-third) as carers is estimated [33, 40, 66]. For the daughters/daughters in law and sons/sons in law, the average cost per hour of paid work (SEK 270) was used [67], whereas for leisure time, we used the opportunity cost per hour as 35% of the average wage [68]. The resulting weighted hourly cost of informal care was SEK 152. In the sensitivity analysis, other costing approaches are presented.

#### **Indirect costs**

Most people with dementia are retired, but those younger than age 65 years are of working age. On the basis of register data from the Swedish Social Insurance Agency, 431 persons were prematurely retired or on sick leave due to dementia diagnoses. This is probably a low

estimate because PWD often are on sick leave for other diagnoses. The figure is also based on the main diagnosis in the register. Furthermore, early retirement or sick leave by other family members is not incorporated into these figures. The unit cost is based on the average wage for the people aged 55–65 years [67] and not on the transfer costs for the retirement or sick leave. The unit costs are summarised in Table 2. Most of the cost sources were derived from official authorities and registers.

### Sensitivity analysis

Owing to the variability in underlying sources and different quantification and costing approaches, several other parameters were tested in a sensitivity analysis. There are many other sources for age class prevalence, and in recent years several studies indicating a decline in prevalence have been presented, although some other estimates suggests an increase (European Brain Council [24], Matthews et al. [8], Lobo et al. [25], SNAC-Kungsholmen [9], EURODEM [26], Alzheimer Cooperative Valuation in Europe [27], EuroCoDe [28] and Alzheimer's Disease International [ADI] [3]). Owing to the discussions regarding the quantification and costing of informal care, several alternative options have been tested: the amount of informal care with supervision added to activities of daily living (in total 4.7 h/day), alternative sources for the amount of informal care (1.5–5.3 h/day in PADL and IADL) [41, 59, 60, 69], various costing of informal care (a zero value, a replacement cost instead of opportunity

cost, SEK 434/h [42] and an alternative source for the opportunity cost [SEK 31/h, based on the Swedish Road Association] [70]). Institutional care costs are one of the heaviest cost drivers in dementia care. Figures regarding the proportion of PWD in different forms of institutional care also vary [30, 32, 33, 51–53, 71], and thus we test an option where the proportion of PWD is lower. The unit costs for institutional care are also varied (25th and 75th percentiles).

### Cost attributable to dementia ('net' costs)

The costs presented as the main option can be regarded as 'gross costs' because they comprise the costs of PWD including costs for conditions other than dementia. One way to estimate costs that are attributable to dementia ('net costs') is to calculate the cost difference between costs for PWD and for people without dementia. The estimates are based on the total direct costs of care for the elderly in Sweden (65 years old and above), which in 2012 were SEK 182 billion, covering 102 billion SEK in the social care sector (municipalities) and SEK 80 billion in the health care sector (the county councils) [38]. Estimates are possible for the population 65 years and older, which represented about 148,000 of the 158,000 PWD in 2012. It is assumed that the costs for PWD aged 65 years and older are the same as those for all PWD. The influence of production losses on PWD was so low that this was not included in the 'net' cost estimates. The net costs can be estimated using a step-by-step procedure (see Table 7 in the Results section below).

**Table 2** Unit costs in base case

|                                      | Unit cost (SEK) <sup>a</sup> | Reference |
|--------------------------------------|------------------------------|-----------|
| Medical care sector                  |                              |           |
| Hospital care                        | 4780/day                     | [49]      |
| Emergency room visits                | 2988/visit                   | [49]      |
| Outpatient care visits (specialists) | 3918/visit                   | [49]      |
| Primary care physician visits        | 1140/visit                   | [83]      |
| Other outpatient care visits         | 931/visit                    | [49]      |
| Drug use                             | 7080/year                    | [55]      |
| Diagnosis in primary care            | 7017/diagnosis               | [84]      |
| Diagnosis in specialist care         | 12,095/diagnosis             | [84]      |
| Social care sector                   |                              |           |
| Higher-staffed institutional care    | 606,134/year                 | [42]      |
| Group living                         | 606,134/year                 | [42]      |
| Lower-staffed institutional care     | 472,828/year                 | [42]      |
| Day care                             | 98,900/year                  | [45]      |
| Home services                        | 434/h                        | [42]      |
| Dementia nurse                       | 56,250/year                  | [48]      |
| Informal care                        | 152/h                        | [67, 68]  |
| Indirect costs                       | 357,600/year                 | [67]      |

<sup>a</sup>1 € corresponds to SEK 8.77 and 1 US\$ to SEK 6.96

## Results

The total societal costs of dementia in Sweden in 2012 were in the base case estimated at about SEK 63 billion (Table 3). By far the most important cost driver is the cost of long-term institutional care (SEK 38 billion). Furthermore, almost 80% of the total costs occur in the municipalities' social care sector. The cost of informal care constitutes 17%, whilst the medical care sector within the county council represents only a small proportion (5%). The costs of drug use constitute almost 39% of the health care sector costs.

When comparing with the previous COI studies [16, 17], some adjustments are needed because the 2012 figures comprise more cost items. The total costs are rather similar in 2000, 2005 and 2012 (Table 4), but while the number of PWD has increased, the cost per PWD has decreased. The main reason for the reduced cost per PWD is that the proportion of PWD who are estimated to be living in institutions has decreased from about 56% in 2000 to 42% in 2012; during that period, the number of institutional beds in Sweden was reduced from about 120,000 in 2000 to 95,000 in 2012.

**Table 3** Total societal costs of dementia in Sweden in 2012 (base option)

|  | Cost (million SEK) <sup>a</sup> | Per PWD, SEK <sup>a</sup> | Proportion |
|--|---------------------------------|---------------------------|------------|
| Medical care sector (county councils)        |                                 |                           |            |
| Hospital care                                | 276                             |                           | 0.4%       |
| Emergency room visits                        | 264                             |                           | 0.4%       |
| Outpatient care visits (specialists)         | 57                              |                           | 0.1%       |
| Primary care physician visits                | 360                             |                           | 0.6%       |
| Other outpatient care (e.g., rehabilitation) | 589                             |                           | 0.9%       |
| Drug use                                     | 1120                            |                           | 1.8%       |
| Diagnostic workups                           | 240                             |                           | 0.4%       |
| Total medical care sector                    | 2904                            | 18,382                    | 4.6%       |
| Social care sector (municipalities)          |                                 |                           |            |
| Institutional care (permanent)               | 38,199                          |                           | 60.7%      |
| Short-term respite care                      | 2364                            |                           | 3.8%       |
| Day care                                     | 989                             |                           | 1.6%       |
| Home services                                | 7372                            |                           | 11.7%      |
| Dementia nurses                              | 338                             |                           | 0.5%       |
| Total social care sector                     | 49,262                          | 311,783                   | 78.3%      |
| Indirect costs                               | 118                             | 744                       | 0.2%       |
| Total <sup>b</sup>                           | 62,920                          | 398,226                   | 100.0%     |

PWD Persons with dementia, SEK Swedish krona

<sup>a</sup>1 € corresponds to SEK 8.77 and 1 US\$ to SEK 6.96.

<sup>b</sup>Discrepancies are due to rounding

**Table 4** Societal cost of dementia (in millions SEK, adjusted to cost level of 2012) in 2012, 2005 and 2000 in different sectors

|                     | 2012              |        | 2005              |        | 2000    |        |
|---------------------|-------------------|--------|-------------------|--------|---------|--------|
|                     | Cost <sup>a</sup> | %      | Cost <sup>a</sup> | %      | Cost    | %      |
| Medical care sector | 2848              | 5.0%   | 2701              | 5.0%   | 3277    | 5.9%   |
| Social care sector  | 44,681            | 78.1%  | 43,275            | 79.4%  | 45,542  | 82.5%  |
| Informal care       | 9534              | 16.7%  | 8065              | 14.8%  | 6017    | 10.9%  |
| Indirect costs      | 118               | 0.2%   | 447               | 0.8%   | 358     | 0.6%   |
| Total costs         | 57,181            | 100.0% | 54,487            | 100.0% | 55,194  | 100.0% |
| Number of PWD       | 158,000           |        | 142,200           |        | 133,000 |        |
| Cost per PWD (SEK)  | 361,902           |        | 383,173           |        | 414,989 |        |

PWD Persons with dementia, SEK Swedish krona

<sup>a</sup>1 € corresponds to SEK 8.77 and 1 US\$ to SEK 6.96. Cost items are adjusted to be similar; thus, costs are not identical to Table 3 for 2012

The most striking finding in the sensitivity analysis is the great range in costs with different approaches of costing informal care (range SEK 7.6 billion–71.5 billion) with a corresponding great variation in total societal cost, ranging from SEK 52 billion to SEK 124 billion (Table 5).

In the other options in the sensitivity analysis (Table 6), the differences vs the base case were smaller. The rather low variation of costs with different prevalence sources is due to an assumed similar proportion of PWD in institutions.

The direct cost that we assumed was related to dementia solely ('net costs') was about SEK 40 billion (Table 7), which constitutes about 76% of the 'gross' direct costs (and about 80% of total societal costs if it is assumed that all informal care is related to dementia).

## Discussion

Three major findings are obvious: (1) The costs of dementia care are very extensive; (2) the majority of the costs occur in the social care sector (the municipalities); and (3) the quantification and costing of informal care are crucial for the cost estimates. When the Swedish figures (total costs of SEK 400,000 [approximately € 45,000, approximately US\$ 57,000]) are compared with other COI figures, the need for transparency is clear. In a review, Jönsson and Wimo found a range between €6000 and €64,000 per case in different European countries, where the main reason for this variation was methodological issues [72]. A similar variation in worldwide COI studies was found in the dementia report by the SBU [23]. In the worldwide cost estimates presented by ADI [1], it was concluded that, besides methodological issues, the interaction between informal care and the social care sector (including, e.g. long-term institutional care) was crucial for the cost differences: low/no resources for long-term institutional care resulted in a high proportion of the costs of informal care and vice versa.

The most important cost driver in Sweden is the cost of institutional care. The institutional concept is wide and includes a variety of care settings where the least common denominator, in our opinion, is staffing around the clock. We have used three institutional levels (nursing homes, dementia-designated care such as group living [73] and residential care alternatives for the aged or similar) to cover the different content of care and costs, and in the sensitivity analysis we have a further variation in costs of institutional care. Although some range occurs in the costs of institutional care in the sensitivity analysis, it is not of the same magnitude as when different approaches for the quantification and costing of informal care were tested [61]. In the literature, there is an extensive variation in the quantity, ranging from 1.5 h to 16 h per day [61, 72, 74–76]. This great

**Table 5** One-way sensitivity analysis of costs of informal care

|   | Hours/day | Hourly cost | Total cost <sup>a</sup> (billion SEK) | Informal care <sup>a</sup> (billion SEK) | Cost per PWD <sup>a</sup> (SEK) |
|---|-----------|-------------|---------------------------------------|--|---------------------------------|
| Base case                                   | 1.9       | 152         | 62.9                                  | 10.6                                     | 398,000                         |
| Higher amount of hours                      | 3.3       | 152         | 70.2                                  | 18.0                                     | 445,000                         |
| Supervision time added                      | 4.7       | 152         | 77.4                                  | 25.4                                     | 490,000                         |
| Replacement cost                            | 1.9       | 434         | 82.6                                  | 30.3                                     | 523,000                         |
| Supervision time added and replacement cost | 4.7       | 434         | 123.8                                 | 71.5                                     | 784,000                         |
| Alternative opportunity cost                | 1.9       | 109         | 59.9                                  | 7.6                                      | 379,000                         |
| Zero cost for informal care                 | 0         | 0           | 52.3                                  | 0  | 331,000                         |

PWD Persons with dementia, SEK Swedish krona

<sup>a</sup>1 € corresponds to SEK 8.77 and 1 US\$ to SEK 6.96

variation depends mainly on how many components of informal care are included; the lower figures represent only PADL support, while the higher figures also include IADLs and supervision/surveillance. Another factor is whether the sources of informal care are based on clinical/convenience samples or on population-based studies, the latter including zero values with lower hourly figures as a result. The costing issue is also crucial, and several methods have been proposed [56, 61–64]. The assumptions used for the mix between informal carers of working age and retired carers also have implications for the costing approach as well as for long-term care policies [77]. Although the opportunity cost is recommended by

most economists, it is not always easy to identify it [65]. Market prices are not available, except for carers of working age, and, in many cases, it is not apparent what the 'best alternative use' of the carers' time is. Thus replacement costs or average wage or suchlike are used in many COI studies, most often resulting in higher costs. Because the different methods of quantification and costing of informal care resulted in such a great difference in final costs, it is obvious that this issue needs transparency but must also be a target for future methodological discussions. Validated instruments are essential where it is clear how informal care is quantified as well as a transparent presentation of how unit costs for informal care

**Table 6** Other one-way sensitivity analyses

| Varied entity  | Value                                   | Cost <sup>a</sup> (billion SEK) | Cost per PWD | Source [reference]  |
|--|---|---------------------------------|--------------|---------------------|
| Prevalence (number of PWD)   | 158,000                                 | 62.9                            | 398,000      | Base case           |
| Prevalence   | 113,000                                 | 54.1                            | 478,000      | EBC [24]            |
| Prevalence   | 117,000                                 | 54.8                            | 469,000      | Matthews et al. [8] |
| Prevalence   | 123,000                                 | 56.0                            | 455,000      | Lobo et al. [25]    |
| Prevalence   | 128,000                                 | 56.6                            | 453,000      | SNAC-K [9]          |
| Prevalence   | 148,000                                 | 60.9                            | 412,000      | EURODEM [26]        |
| Prevalence   | 151,000                                 | 61.5                            | 408,000      | ALCOVE [27]         |
| Prevalence   | 168,000                                 | 64.9                            | 386,000      | EuroCoDe [28]       |
| Prevalence   | 169,000                                 | 65.1                            | 385,000      | ADI [3]             |
| Home care: per executed hour                                       | 558                                     | 63.8                            | 404,000      |                     |
| Home care: median hourly cost                                      | 420                                     | 61.6                            | 390,000      | [42]                |
| Home care: 25th percentile per hour                                | 378                                     | 60.9                            | 385,000      | [42]                |
| Home care: 75th percentile per hour                                | 473                                     | 62.5                            | 395,000      | [42]                |
| Institutional care: 25th percentile (low staffed and high staffed) | 363,920 and 565,811                     | 59.1                            | 374,000      | [42]                |
| Institutional care: 75th percentile (low staffed and high staffed) | 534,142 and 639,828                     | 65.6                            | 416,000      |                     |
| Institutional care: proportion PWD                                 | 50% in low-staffed, 80% in high-staffed | 64.2                            | 406,000      |                     |
| Institutional care: proportion PWD                                 | 40% in low-staffed, 50% in high-staffed | 59.1                            | 374,000      |                     |

PWD Persons with dementia, SEK Swedish krona

<sup>a</sup>1 € corresponds to SEK 8.77 and 1 US\$ to SEK 6.96

EBC European Brain Council

**Table 7** Estimated 'net' costs of dementia (SEK)

|   | Social care sector | Medical care sector | Total               |
|---|--------------------|---------------------|---------------------|
| Step 1  |                    |                     |                     |
| Direct cost of care for people aged 65+ years                                   | 101,756            | 79,973              | 181,729 million SEK |
| Direct costs of dementia  | 49,262             | 2904                | 52,166 million SEK  |
| Direct costs for PWD aged 65+ years <sup>a</sup>                                | 46,144             | 2720                | 48,864 million SEK  |
| Direct costs of care for people without dementia aged 65+ years                 |                    |                     | 132,865 million SEK |
| Number of people aged 65+ years   |                    |                     | 1,828,283           |
| Number of people aged 65+ years without dementia                                |                    |                     | 1,680,283           |
| Direct cost per person aged 65+ years without dementia                          |                    |                     | 79,073 SEK          |
| Step 2: costs per PWD   |                    |                     |                     |
| Gross cost per person with dementia <sup>a</sup> (Table 2) <sup>b</sup>         |                    |                     | 398,226 SEK         |
| Exclude: direct cost for person without dementia as above                       |                    |                     | 79,073 SEK          |
| Exclude: costs of informal care of PWD (Table 2)                                |                    |                     | 67,318 SEK          |
| 'Net' direct costs  |                    |                     | 251,836 SEK         |
| 'Net' total costs (including informal care)                                     |                    |                     | 319,154 SEK         |
| Step 3: aggregated costs  |                    |                     |                     |
| Aggregated 'net' direct costs of dementia aged 65+ years (148,000 PWD)          |                    |                     | 37,272 million SEK  |
| Aggregated 'net' direct costs all dementia (158,000 PWD)                        |                    |                     | 39,790 million SEK  |
| Aggregated 'net' costs all including informal care aged 65+ years (148,000 PWD) |                    |                     | 47,235 million SEK  |
| Aggregated 'net' costs all including informal care all dementia (158,000 PWD)   |                    |                     | 50,426 million SEK  |

PWD Persons with dementia, SEK Swedish krona

<sup>a</sup>Assumptions: similar for PWD aged 65+ years as for all PWD and adjustment factor (here, dementia aged 65+ years only) 148,000/158,000

<sup>b</sup>1 € corresponds to SEK 8.77 and 1 US\$ to SEK 6.96

are obtained and valued. A sensitivity analysis is crucial to highlight the variability and to make comparisons with other studies possible.

The relatively high proportion (39%) of drug costs in the total costs of the county councils may have several explanations. First, the county councils pay for all drug use of PWD, even if, for example, they are cared for in municipal nursing homes. Second, the costs of hospital care as well as the costs of outpatient specialist care are based on register data, where a diagnosis of dementia often is not registered even if a patient has a dementia disorder [78]. Thus, these costs may be underestimated, resulting in a relatively higher proportion of the costs of drugs for the county councils. In contrast, even if there is a debate regarding the prevalence of dementia [7–11], the use of different prevalence sources in the sensitivity analysis did not alter the COI figures significantly.

Although the societal costs of dementia are substantial, the costs per person were lower in 2012 than in 2000 and 2005. The main reason is the de-institutionalisation trend in Sweden. The number of long-term care beds in institutions in Sweden (persons aged 65 years and above)

decreased from about 119,000 in 2000 to 100,400 in 2005 and 90,500 in 2012 [79], which resulted in lower costs (per person) in 2012 than in 2000 and 2005. Consequently, the relative impact of costs of informal care has increased. This reflects, at the same time, a gradual shift of responsibilities from the state to the families. The question whether this is good or bad cannot be answered by a COI study. There are no assessments of the quality of care or the quality of life of PWD or the informal carers in our data. Such consequences can be analysed with instruments such as DEMQOL (for PWD) [80] or CarerQol (for informal carers) [81], and they are usually incorporated as outcomes in cost-effectiveness analysis of interventions. In light of expected demographic changes, with a considerably rapid increase in the numbers of people aged 80 years and older after 2020 [82], these trends in the change of the care structure need a profound analysis.

It is obvious that transparency is crucial in COI studies, otherwise comparisons are not meaningful. A comprehensive and transparent sensitivity analysis also highlights different analytical approaches, which makes comparisons with other COI studies easier.



## Conclusions

The societal costs of dementia are very high. The cost per PWD has decreased somewhat, mainly because of de-institutionalisation. The majority of the costs occur in the social care sector, but the costing of informal care is crucial for the cost estimates.

## Abbreviations

ADI: Alzheimer's Disease International; ALCOVE: Alzheimer Cooperative Valuation in Europe; EBC: European Brain Council; COL: Cost of illness; IADL: Instrumental activities of daily living; NBHW: Swedish National Board of Health and Welfare; PADL: Personal activities of daily living; PWD: Persons with dementia; RUD: Resource Utilization in Dementia; SALAR: Swedish Association of Local Authorities and Regions; SBU: Swedish Agency for Health Technology Assessment; SEK: Swedish krona; SNAC: Swedish National Study on Aging and Care; SveDem: Swedish Dementia Registry

## Acknowledgements

We are grateful for the support in data collection provided by the memory clinics in Sweden, SveDem and the statistical department at the Swedish Social Insurance Agency.

## Funding

Funding for this study was provided by Swedish Brain Power; the Swedish Ministry of Health and Social Affairs; the Swedish National Board of Health and Welfare; and the Centre for Research & Development, Uppsala University/County Council of Gävleborg, Gävle, Sweden.

## Availability of data and materials

All calculations are made in Excel. If the editor wish to see these files, they need to be edited because the cost estimates have been done during several years with complex interactions and links between sheets.

## Authors' contributions

AW had the main responsibility for preparing and drafting the manuscript, and he made substantial contributions to study design, acquisition of data, and analysis and interpretation of the results. Ljö n was involved in study design as well as analysis and interpretation of results, and he made significant intellectual contributions to the manuscript. LF was involved in acquisition of data as well as analysis and interpretation of the results, and she made significant intellectual contributions to the manuscript. POS was involved in acquisition of data as well as analysis and interpretation of the results, and he made significant intellectual contributions to the manuscript. AG was involved in study design as well as analysis and interpretation of results, and he made significant intellectual contributions to the manuscript. AS was involved in acquisition of data as well as analysis and interpretation of the results, and he made significant intellectual contributions to the manuscript. Ljö h was involved in study design as well as analysis and interpretation of results, and he made significant intellectual contributions to the manuscript. All authors read and approved the final manuscript.

## Authors' information

AW co-authored the 2010 and 2015 World Alzheimer Reports.

## Competing interests

None (see also funding information under Acknowledgements heading). Outside the submitted work, AW has attended expert meetings with Novartis and Lundbeck, has received a grant from Nutricia (payment to Karolinska Institutet) and participates on an advisory board for Eli Lilly (payment to Karolinska Institutet); Ljö n is an employee of Lundbeck; and AG is a partner at Quantify Research. All other authors declare that they have no competing interests.

## Consent for publication

Not applicable.

## Ethics approval and consent to participate

Because this paper is based on secondary sources and no individual persons with or without dementia were involved, there was no need for ethical permission or consent to participate.

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Received: 29 June 2016 Accepted: 14 October 2016

Published online: 18 November 2016

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