

New model giving insight in group of 256 thousand people living with dementia in the Netherlands

A new model gives a reliable insight in the group of people currently living with dementia in the Netherlands.

Introduction

Dementia is a syndrome with a big impact on the lives of patients and their beloved ones. In the Netherlands the facts about the number of people living with dementia, the health care they use and the costs of good dementia care are still based on guesstimates.

Vektis has the complete dataset about health care claims in the Netherlands. Therefore Vektis is able to give a factual insight in how many people in the Netherlands live with dementia and what kind of health care they use.

All estimates about the prevalence of dementia in the Netherlands are based on the ERGO-study (Erasmus Rotterdam Gezondheids Onderzoek) from the nineties. The ERGO-study was carried out between 1989 and 1993 in the neighbourhood Ommoord in the city of Rotterdam, among 7.528 citizens of 55 year and older.

The value of these estimates is limited by the fact that the study was conducted more than 20 years ago and that we do not know if the population of Ommoord is representative for the whole of the Netherlands.

The method developed by Vektis gives an up-to-date and almost complete image of the dementia population in the Netherlands.

Methodology

Vektis has the data about all the healthcare claims in the Netherlands. (namely: from General practitioner [and all other kinds of primary healthcare], hospital, mental healthcare to nursing homes and home care) Vektis receives data from all the health insurance companies in the Netherlands. Based on this data Vektis can provide, a complete picture of the healthcare used while ensuring anonymity. Vektis also receives data from the admission system for nursing homes. To establish the group of people having dementia we investigate which healthcare claims are related to dementia. For each of these specific health care costs we check whether it can be used to include someone in the group of people having dementia.

The next step is to establish the group having these specific health care costs, whereby we exclude people younger than 40 years old. Thus a group of people having dementia in the Netherlands is established.

Criteria used to establish the group of people living with dementia

None of the health care claims from the general practitioner in the Netherlands are dementia specific. In the health care claims of hospital, nursing home, home care and mental care we find claims regarding dementia and some of these could be used as criteria to establish the group of people living with dementia.

To establish the group of people living with dementia in the year 2017, we used the healthcare claims from the years 2008-2018. We use healthcare claims from the years before 2017, because if someone was diagnosed with dementia in 2009 and is still living in 2017, he or she will still be living with dementia.

We used different verification methods for our inclusion criteria to be as certain as possible that the only people we include are people living with dementia. Therefore, we looked at the age distribution of criteria, we looked at the coherence and interdependence between the

criteria, and we consulted medical experts. Finally, we compared our dementia population with results of both national and international surveys. This process led to a sharpening of our criteria (and loss of some potential inclusion criteria). The inclusion criteria are:

Healthcare sector	Criteria
Medication (2008-2017)	<ul style="list-style-type: none"> - Galantamine (N06DA04) - Memantine (N06DX01) - Rivastigmine (N06DA03) - Donepezil (N06DA02, N06DA52, N06DA53)
Hospital care (2008-2017)	<ul style="list-style-type: none"> - Diagnosis 0401 (Dementia syndrome) neurology department (0330) - Diagnosis 0091 (Memory problems and dementia) internal medicine department (code: 0313) - Diagnosis 0242 (Memory problems and dementia) clinical geriatrics department (0335)
Mental care (2008-2017)	<ul style="list-style-type: none"> - 007, Delirium, dementia, amnesic and other cognitive disorders
Nursing home care (normal) (2012-2018)	<ul style="list-style-type: none"> - Z051, Z053: care intensity package 5VV¹ in a nursery home - V051, V053: care intensity package 5VV home care - H533: psycho geriatric day care
Nursing home care (personal budget) (2012-2018)	<ul style="list-style-type: none"> - Healthcare base = 02, this mean healthcare based on psycho geriatric disease is needed. 2012-2015 - Care intensity package 5VV
Admission system nursing homes (Information system with medical data which is the basis for getting admission to nursing home care, reference date 1 January 2018)	<ul style="list-style-type: none"> - Healthcare base = 02, this mean healthcare based on psycho geriatric disease is needed.
Home care (2017)	<ul style="list-style-type: none"> - 1035: Care for vulnerable elderly and chronically ill, longer than 3 months (psychogeriatric / psychiatric)

Table 1. Dementia criteria by healthcare sector

In the figure below the dementia prevalence from Vektis is compared with other research.

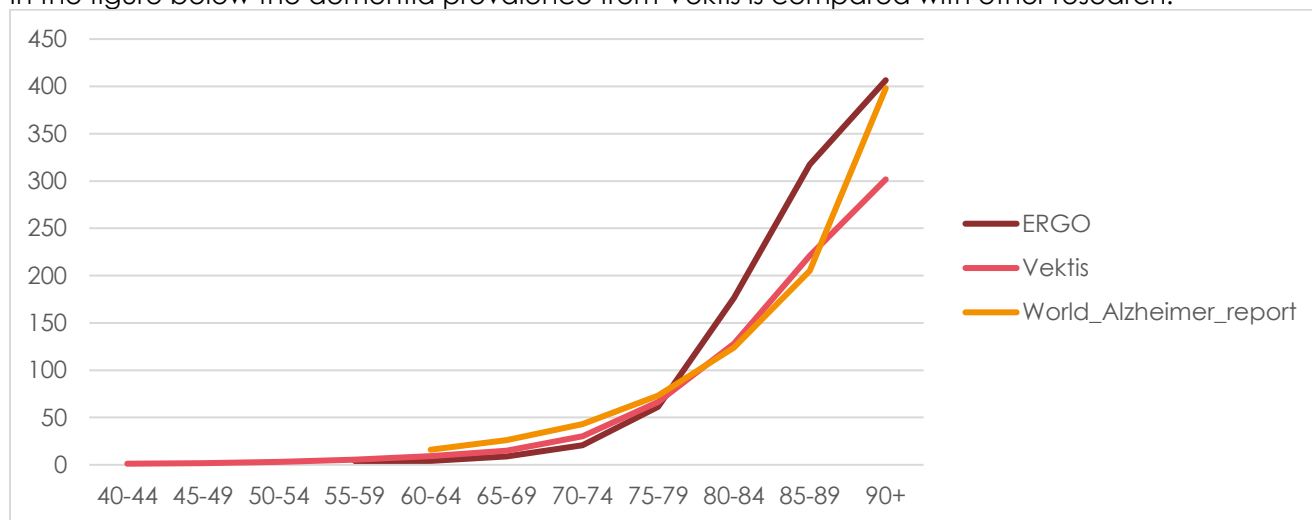


Figure 1 Prevalence of dementia per 1000 people according to age compared with other research. Sources: "ERGO, Prevalence of Alzheimer's syndrome and vascular dementia: association with education. The Rotterdam study, Ott et al. 1995" and "Alzheimer's Syndrome International World Alzheimer Report 2015, The Global Impact of Dementia, An analysis of prevalence, incidence, cost & trends van Prince et al. 2015"

¹ The 5VV package is described as 'Protected living with intensive guidance and comprehensive care' This package is meant for people with dementia in nursing home care.

Dementia population and healthcare utilization

Using the above criteria Vektis establishes a total group of 256.000 people living with dementia during the year 2017. 39 Thousand people living with dementia who passed away during 2017 are included in this number.

61% Of the people living with dementia are women and 39% are men. If we look at dementia by age, the number of people living with dementia is the highest at the age of 85. More than 12 thousand people of 85 years old live with dementia. This is 19% of the total 85-year-old population. If we divide the group of people not only by age but also by gender, the number of people living with dementia is highest among men at the age of 82 and among women at the age of 86. Dementia is not something only for the elderly. There are more than 24 thousand 40-65-year-old people living with dementia. If we look at the prevalence numbers we see that by the young people living with dementia the prevalence by men is higher. From 75 years and older the prevalence by women is higher.

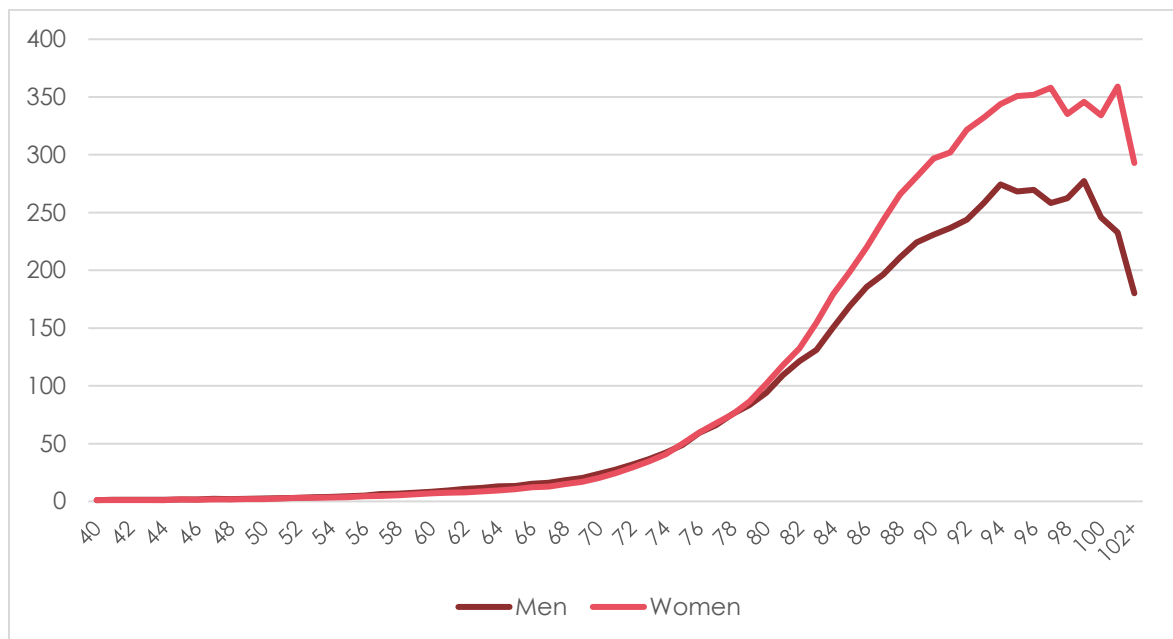


Figure 2 Dementia prevalence per 1000 people according to gender and age

The group of people living with dementia can also be divided by the place where they live. In the last week of January 2017 there were 175 thousand people living at home (2/3 of the population) and 82 thousand people (the other 1/3) living in a nursing home.

During the year 2017 patients living at home received 21.500 euro healthcare per person. From this 21.500, 9.100 euro is for nursing home care, these costs are explained because some patients receive nursing home care at home and some moved during 2017 to a nursing home.

The patients whom in January 2017 lived in a nursing home used more than three times as much healthcare during that year, receiving almost 68.000 euro per person. The major part of this care is the cost for the care in the nursing homes.

Discussion

Vektis has discussed the results of this research with patient organization Alzheimer Netherlands. Based on the estimates of Alzheimer Netherlands Vektis has included more than 80 percent of the people living with dementia. Nevertheless, Vektis misses approximately 50 thousand people of the total dementia population of the year 2017. These are people who live at home, have a light form of dementia and only receive some basic form of help at home (WMO), informal care or do not (yet) make use of care at all.

Vektis uses healthcare claims more often to shed some light on certain healthcare populations. For example people with chronic syndromes like diabetes or COPD/asthma

and people with Parkinson. Not every population can easily be distracted from healthcare claims. To find good dementia criteria is hard, because the healthcare claims related to dementia are diverse and the diagnosis 'dementia' is not unambiguously available. Therefore, we have used healthcare claims from the whole healthcare range, diverse methods for verification and a period of ten years of data. With this effort we have managed to get some grip on the prevalence of dementia and found a group of people living with dementia which in terms of number of people and prevalence by age can be well compared with national and international resources. Vektis finds more people with dementia in the young age of 40-65 years old than experts until now have estimated. Furthermore it is interesting to see that we find a lower prevalence in the age group 90 years and older compared to ERGO and the World Alzheimer Report. Both these facts might be interesting: can they help to improve the (inter)national prevalence estimates?

Yield

By establishing the group of people living with dementia in the Netherlands we are able to see the full healthcare consumption of this group on each required level. We use this for example in dementia reports per town and per dementia region. Towns, dementia organizations and health insurance companies are therefore able to view how many people with dementia there are per neighbourhood and what kind of healthcare they use. We are also able to follow trends in time. For example, what kind of health care do people use in the years before they are diagnosed with dementia? Or how do healthcare costs develop in the first years of dementia? This may give valuable directions to improve (local) dementia policies, which is badly needed because we face a big increase of the dementia population due to the ageing population of the Netherlands.

Conclusion

Vektis is able to give an almost complete view on the group of people living with dementia in the Netherlands. This makes it possible to give insights in the integral healthcare of people living with dementia at every required level, intersection or slide. This may help healthcare providers, healthcare insurance companies, towns, patient federations and other healthcare parties to improve the dementia care in the Netherlands.

Authors

Henri van den Pol (E: H.van.den.Pol@vektis.nl T: +3130 8008 386)

Ronald Luijk

Evelien Leegwater

The research report is at the moment only in Dutch available and can be downloaded here:

<https://www.vektis.nl/nieuws/zorggebruik-van-mensen-met-dementie-in-beeld>

Address Vektis:

Sparrenheuvel 18, Gebouw B, 3708 JE Zeist

T: 030 8008 300

F: 030 8008 320

E: info@vektis.nl