



DEMENTIA-FREE LIFE EXPECTANCY (DemFLE) IN THE NETHERLANDS

ROM J. M. PERENBOOM,^{1*} HENDRIEK C. BOSUIZEN,¹ MONIQUE M. B. BRETILER,² ALEWIJN OTT² and HARRY P. A. VAN DE WATER^{1*}

¹TNO Prevention and Health, PO Box 2215, 2301 CE Leiden and ²Erasmus University Medical School, Department of Epidemiology and Biostatistics, PO Box 1738, 3000 DR Rotterdam, The Netherlands

Abstract—To gain an insight into the burden of dementia in an aging society, life expectancy with dementia and its counterpart dementia-free life expectancy (DemFLE) in The Netherlands are presented. Sullivan's method was used to calculate DemFLE. For elderly living either independently or in homes for the elderly prevalence figures on dementia were obtained from the Rotterdam Elderly Study (RES; $n = 7528$); for elderly in nursing homes the SIG Nursing home Information System was used. Conforming to other authors only the prevalence data on moderate and severe dementia as diagnosed with DSM-III-R criteria are used. The prevalence of mild dementia was not taken into account. At 65 years DemFLE for men is 14.0 years, that is 96.4% of the total life expectancy (14.5 years at this age). At age 90, DemFLE for men is 2.5 years, equal to 77.5% of the total life expectancy (3.3 years). For women DemFLE at age 65 is 17.7 years, that is 93.2% of their life expectancy (19.0 years), and at the age of 90, DemFLE for women is 2.8 years, equal to 74.7% of their remaining life expectancy (3.8 years). The absolute number of years with dementia remains relatively constant with increasing age. About 20–25% of these years with dementia are spent in nursing homes, the other 75–80% living independently. At each age compared with men women have both a higher DemFLE and a higher expectancy of years with dementia. The percentage of life expectancy without dementia however, is always lower for women, because of their higher total life expectancy. This indicates that the burden of dementia in absolute and relative terms is higher for women. Most years with dementia are spent at home, indicating that the burden of dementia rests mainly on the shoulders of informal caregivers. Copyright © 1996 Elsevier Science Ltd

Key words—health expectancy, dementia, epidemiology, life expectancy

INTRODUCTION

With the aging of society mortality figures and derived indicators like total life expectancy are losing in health policy relevance, because they do not take into account the increasing amount of non-lethal, chronic-degenerative diseases occurring with age. Health expectancy is a relatively new indicator which combines data on morbidity and mortality and thus gives a better insight into the health status of the population. Health expectancies have now been calculated in about 37 countries in the world [1, 2]. Due to the use of different concepts of health the results are not easily compared between countries [3], though most of the calculations have in common that they are focused on physical disabilities [1]. In the Netherlands emphasis in health expectancy research has also been on physical disabilities [4–6]. Mental disorders having received so little attention [7–9] the International Network on Health Expectancies and the Disability Process (REVES) and the European concerted action Euro-REVES [10] have nominated special committees focusing on the inclusion of mental disorders in health expectancy calculations,

with special attention to dementia [11]. Priority has been given to dementia because the prevalence of dementia strongly increases with age [12], so that in the aging Western populations dementia is a problem of increasing proportions. Kramer even talks about a “rising pandemic of mental disorders and associated diseases and disabling conditions” [13].

Main symptoms of dementia are cognitive impairment, affective impairments, changes in personality and reactive symptoms [14]. These symptoms lead to a rapid loss of autonomy and independence and thus cause a considerable burden on (professional and informal) caregivers. Only an estimated 11% of the total number of dementia cases is reversible because the underlying causes are treatable (drugs, depression etc.) [15]. Therefore, the majority of cases will need long term care. For the organization of care information on what the burden of this disease is, is important. To gain insight in the burden of dementia in the Netherlands, we calculated life expectancy with dementia and dementia-free life expectancy (DemFLE).

METHODS

DemFLE is calculated from the sex and age-specific prevalence of dementia with the observed life

*Author for correspondence.

table method (Sullivan's method) [1, 16], by partitioning total life expectancy into the number of years that may be assumed to be spent with and without dementia. This is done on the basis of age-specific dementia prevalence data. Once the life table is modified in this manner, the period life expectancy according to the states of dementia is calculated in the traditional manner: dementia-free life expectancy and life expectancy with dementia. To compare the results between the sexes and with other countries, the absolute number of years are not sufficient, because of the differences in life expectancy, for instance between the sexes. For this reason dementia-free life percentages are also calculated; that is, the ratio between dementia free life expectancy and total life expectancy.

To calculate total life expectancy, we used the age and sex-specific mortality figures for 1993, provided by the Netherlands Central Bureau of Statistics. To estimate the prevalence of dementia in the Dutch population, we used data from the Rotterdam Elderly Study (RES) [17, 18]. The RES is a longitudinal study into different health aspects in the elderly (of 55 years and over) in a suburb of Rotterdam. One of these aspects is dementia [19]. From the 10,275 inhabitants of 55 years and older, 78% (7983) were included in this study. Due to deaths and refusals, 7528 (73%) respondents were included in the substudy on dementia. Although the distribution over the age groups slightly differs from the total Dutch population of 55 years and over the population seems reasonable representative for the total group of Dutch elderly living either independently or in homes for the elderly. The methods used to estimate the prevalence of dementia of the substudy having been extensively reported elsewhere [19], only a brief summary of the methodology is given here. Dementia was diagnosed in a three-phase procedure. First, all included respondents were screened with a combined Mini Mental State Examination (MMSE) [20] and Geriatric Mental State Schedule (GMS-A, organic level) [21]. Screen-positives (MMSE score of 25 or below, or a GMS score of 1 or over) were examined by a physician with the CAMDEX diagnostic interview [22]. In the last stage participants with a score of less than 80 points on the CAMDEX and those with higher scores who were suspected of dementia by the physician were extensively examined. This included an examination by a neurologist, an MRI-scan and a test by a neuropsychologist. Diagnostic information on those participants who refused the CAMDEX or who lived in psychogeriatric departments of the homes for the elderly was obtained from GPs and physicians in the homes for the elderly. Dementia was diagnosed according to the DSM-III-R criteria [14], which means that only the DSM-III-R prevalence rates are used.

The RES does not include data on the population in nursing homes, so we had to obtain these data from another source. One way is to draw a sample

from the nursing home population, to estimate the prevalence, but fortunately in the Netherlands there exists a central registration system for nursing home data. Almost all nursing homes in the Netherlands provide data on all their patients to this central registration system, the SIG Nursing Home Information System. These data include gender and age, but also the main diagnosis of all the patients and even allows for two subdiagnoses per patient. For our study, we obtained data from the SIG Nursing Home Information System regarding those patients in the nursing homes in 1993 who are diagnosed as demented. Because data were not available for approximately 8.2% [23] of the psychogeriatric beds, the data have been corrected by adding 8.2% to each age and sex group, thus assuming that the distribution of dementia over age and sex for the missing beds are the same as for those included in our data. Including these missing, in the Dutch nursing homes in 1993 there are 4950 men and 15,950 women diagnosed as demented.

Because estimation of the prevalence of mild dementia is problematic [12], and because of international comparability [7-9], in this paper we restrict dementia to moderate and severe dementia. In the RES, severity of dementia is based on the Clinical Dementia Rating Scale and the Global Deterioration Scale [18]. No information is available on the severity of dementia for the nursing home population, but it seems plausible that most of them are suffering from moderate or severe dementia [24].

In the results, life expectancy with dementia will be divided in years spent in nursing homes and years living independently, thus not only providing information on the burden of this disease as such, but also by different living situations.

RESULTS

Although DemFLE "at birth" is included in the tables, the results are more interesting above the age of 65 years, so results from these higher ages are described in greater detail. In Tables 1 and 2 as well as in Fig. 1 total life expectancy, life expectancies with dementia and DemFLE are presented for men and women by five year age intervals. The Tables and Fig. 2 also present the percentages of total life expectancy that can be expected to be free of dementia (DemFLP).

At the age of 65 years, life expectancy for men is 14.5 years and for women 19.0 years. Men of 65 years can expect to live 14 years without dementia, that is 96.4% of their total life expectancy. For women, these figures are 17.7 and 93.2%. The absolute number of years with dementia increases slightly with age until the age of 80 (for women) or 85 (for men) and then decreases. At the age of 80, women can expect to live another 8.3 years, of which 82.3% (6.8 years) without dementia. Men at 85 have a total life expectancy of 4.6 years and a DemFLE of 3.7 years

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