Dementia in older persons

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This is a data brief from The Older Persons and Informal Caregiver Survey Minimum DataSet (TOPICS-MDS). TOPICS-MDS is an excellent resource on the health and wellbeing of a large number of frail older persons and their caregivers across the Netherlands, collected within the National Care for the Elderly Programme (NPO). TOPICS-MDS data briefs provide updates on TOPICS-related research findings to health professionals, policy makers and other relevant agencies, thereby contributing to the evidence base for health services programmes.

Introduction

Dementia is an age-related chronic syndrome and is characterized by progressive cognitive decline, which interferes with independent functioning. Elderly people with dementia are not always able to carry out their daily activities. This may compromise their autonomy and capacity to live independently, giving rise to dependence on others and a demand for care. As a result, dementia is often experienced as a devastating disease. Not only for the person affected, but also for family members, caregivers and society as a whole. In the coming years the demand on caregivers is expected to increase, because the number of people with dementia is rising.

Dementia in the Netherlands (*Alzheimer Nederland, 2014*)

- About 260,000 individuals have dementia, 95% is older than 65 years.
- By 2040 the number of people with dementia will likely to be doubled and have reached an number of over half a million.
- Dementia is a disease associated with the highest disease burden.
- High health care costs are involved in dementia: In 2014, health care costs amounted to more than 4 billion, which corresponds to 5% of total health care costs. It is expected that these costs will increase annually by 2.7%.
- 70% of individuals with dementia live at home and are being cared for by caregivers.
- Some 300,000 provide care for someone with dementia. On average, they spend 20 hours a week on caregiving, for a period of 5 years.

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260,000 persons have dementia.
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(Alzheimer Nederland, 2014)

Dementia report in TOPICS-MDS

TOPICS-MDS is a national database with longitudinal information on the health and wellbeing of over 38,000 older persons and 4,000 caregivers from the general population, primary care, hospitals, and nursing homes across the Netherlands. For more information about this database, please visit our website: ***www.topics-mds.eu***. Currently TOPICS-MDS includes data from 29,655 Dutch older persons (≥ 65 years), who have responded to the question whether they have a form of dementia. Of these participants, 5.2% (n = 1,809; 45.1% male) reported having dementia. Table 1 shows the characteristics of the older persons, stratified by self-reported dementia status. Participants who reported having dementia were older and received lower formal education than participants without dementia. Furthermore, of the chronic diseases that generally are associated with dementia, particularly stroke/TIA and depression appear to be more common in participants with self-reported dementia, compared to participants without dementia.

Table 1. Characteristics (%) of older persons (≥ 65 years of age) in TOPICS-MDS, stratified by self-reported dementia status.

	No dementia (n=27,846)	Dementia (n=1,809)
Gender (male)	39.6	45.1
Age		
65-70 years	7.9	7.0
70-75 years	21.1	13.1
75-80 years	27.5	25.2
> 80 years	43.5	54.7
Marital status		
Married/living together	49.5	55.1
Partner deceased	39.4	37.8
Single/divorced	11.1	7.1
Living situation		
Alone	43.6	34.2
With family	54.0	59.0
Residential care	2.4	6.8
Education		
Low	22.2	26.7
Middle	60.3	58.0
High	17.5	15.3
EQ-5C* (cognitive functioning)		
No problem	68.4	23.0
Some problems	30.3	54.5
Serious problems	1.3	22.5
Chronic disease		
Heart failure	21.3	18.9
Diabetes	21.3	23.5
Stroke/TIA	8.2	13.1
Depression	8.2	15.9
≥ 2 of these diseases	11.8	15.4

*Health related quality of life – cognitive functioning: memory, attention and thinking

Dementia and frailty

Frailty refers to a state of increased susceptibility to adverse health outcomes in older persons. Frailty levels can be estimated from physical, psychological and social health problems reported by older persons. Assessment of frailty may be particularly beneficial for older persons with dementia, since it can serve as a marker for vulnerability to other adverse health outcomes. In TOPICS-MDS, frailty levels are estimated by using a validated Frailty Index (TOPICS-FI) based on multiple domains (see TOPICS-MDS Data Brief no. 2 for details).

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Visit **www.topics-mds.eu** for more information on available data and details about the data application procedure

Figure 1 shows that the frailty index score, as calculated with the 45-item TOPICS-FI, increases with age. In addition, older persons with self-reported dementia appear to have consistently higher TOPICS-FI scores than older persons without dementia.

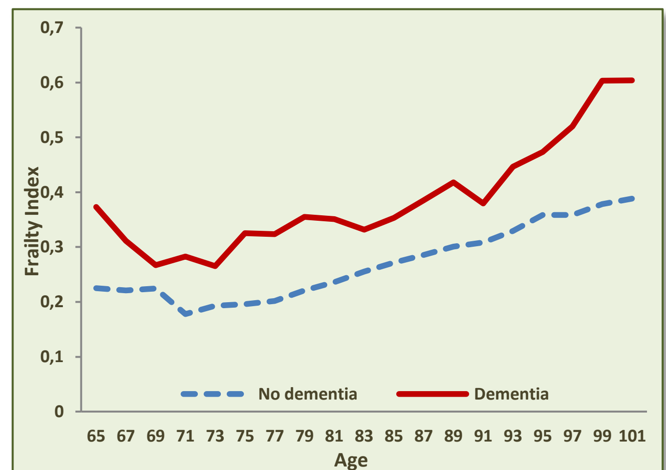

Figure 1. TOPICS-FI increasing with age, stratified by self-reported dementia status.

Dementia and sub-domains of TOPICS-FI

The TOPICS-FI is based on five subdomains: Multimorbidity, functional limitations, health-related quality of life, psychological well-being and social functioning. Figure 2 shows the difference in the five domains between older persons with and without self-reported dementia, making use of the standardized TOPICS-FI (0-1; higher is worse). The difference in frailty index scores can be explained mainly by differences in functional limitations and health-related quality of life.

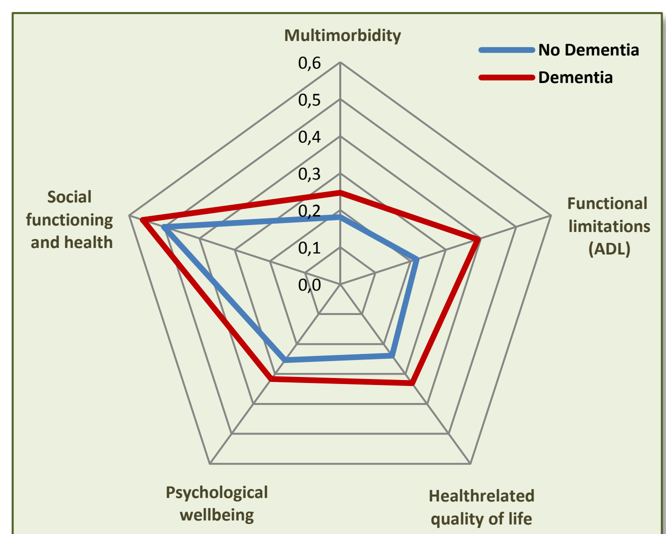

Figure 2. The five sub-dimensions of TOPICS-FI for determining the burden of dementia in older persons (≥ 65 years of age).

Dementia, frailty and overall health care costs

Dementia status and the level of frailty may affect health care costs independently of each other. It is therefore relevant to better understand the extent to which the separate and/or combined effect of dementia and frailty are associated with more intensive care use and higher health care costs. In TOPICS-MDS, health care costs are estimated based on reported hospitalizations, emergency care issued by the GP, home care, day care and stay in a care or nursing home, 12 months prior to assessment. Figure 3 shows that for older persons with self-reported dementia in the lowest and middle TOPICS-FI tertiles, care costs were not higher than for the elderly without dementia. However, for older persons in the highest TOPICS-FI tertile, having dementia is associated with higher health care costs.

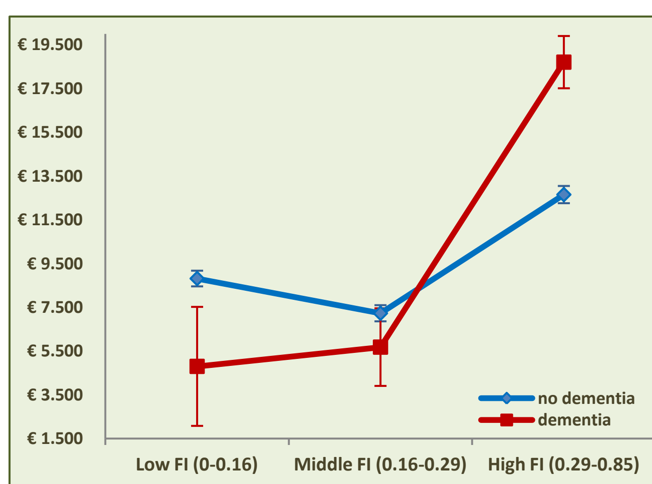

Figure 3. Health care costs stratified by dementia status and TOPICS-FI tertile group in older persons (≥ 65 years of age).

Dementia, younger and older age

Persons younger than 65 years who are diagnosed with dementia, are often described by health care professionals as 'younger people with dementia'. The symptoms of dementia may be similar regardless of a person's age, but younger people may have different needs, and require different support. Of the 1,855 individuals with self-reported dementia in TOPICS-MDS 2.5% (n = 46) was younger than 65 years (Table 2). This group tended to report more problems in cognitive functioning. By contrast, multimorbidity does not appear to occur more frequently in this group than in the age group of 65 to 80 years. The TOPICS-FI and estimated total health care costs were higher for the higher age groups.

Table 2. Characteristics of older persons with self-reported dementia (n=1,855), stratified by age group.

Age	<65 (n=46)	65-80 (n=819)	≥80 (n=990)
EQ-5C (cognitive functioning)			
No problems	9.7	28.4	18.6
Some problems	71.0	54.2	54.8
Serious problems	19.4	17.4	26.6
Chronic diseases			
Heart failure	8.7	16.4	20.9
Diabetes	10.9	25.2	22.0
Stroke/TIA	2.2	13.7	12.6
Depression	21.7	16.2	15.7
≥ 2 of these diseases	4.3	15.1	15.7
Multimorbidity*			
3-5 diseases	26.1	31.3	32.6
≥ 5 diseases	8.7	17.6	24.3
Quality of life§ (0-10, higher is better)	6.5 (1.8)	6.8 (1.4)	6.9 (1.5)
Frailty index§ (0-1 higher is worse)	0.32 (0.1)	0.31 (0.2)	0.37 (0.2)
Estimated overall care cost (in thousand €)§	3.2 (3.6)	8.1 (18)	15.4 (26.6)

*Based on 16 self-reported chronic diseases, excluding dementia
§ Mean (SD)

Questions that could be answered using TOPICS-MDS

- *What are the multiple adverse conditions and functional limitations in older persons, due to dementia?*
- *What is the prospective utility of TOPICS-FI in stratifying sub-clinical groups of dementia patients?*
- *What is the prospective quality of life and dementia?*
- *What is the association of TOPICS-FI and dementia with care costs?*
- *What is the perceived burden of informal caregivers for dementia patients?*

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