Young-Onset Dementia: An Overview of the Epidemiology and Costs in Flanders, Belgium. Recommendations for Further Scaling and Diffusion of Innovations

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RESEARCH

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ABSTRACT

Young-Onset Dementia (YOD) is typically characterised as onset before the age of 65 years and represents a heterogeneous group of cognitive disorders. The wide range of clinical presentations results in a significantly higher time to diagnosis compared to dementia in the elderly. When diagnosed, limited social and professional support can have devastating psychosocial consequences for the patient, family and caregivers; resulting in a lower quality of life (QoL).

YOD only recently has received more attention in research and policy. As different policy approaches for both YOD and Late-Onset Dementia (LOD) are needed, more research on YOD epidemiology, costs and psychosocial consequences is necessary. This report aims to give an overview of the available data on YOD epidemiology and costs in Flanders, Belgium. In addition, several Flemish initiatives focusing on YOD are discussed with recommendations for further policy improvement at multiple levels, including for application beyond Flanders.

Key Words: young-onset dementia; early-onset dementia; costs; epidemiology; Flanders; policy.

1. INTRODUCTION

Globally around 152 million people will live with dementia by 2050 [1]. The majority of these cases will be patients with Late-Onset Dementia (LOD); diagnosis at the age of ≥ 65. In 2015, in the Flemish region of 6.6 million inhabitants, the total number of people with dementia was estimated at 122 161. Among this group approximately 5461 people have Young-Onset Dementia (YOD), from which roughly 1800 persons have been formally diagnosed. As the number of inhabitants aged 30-64 years old tends to decrease in the upcoming years, the total number of people with YOD will remain roughly constant or slightly decrease [2], [3]. Similarly, LOD, YOD can be subdivided in several subtypes with Alzheimer's disease (AD) as most frequent categorisation in both groups. Larger differences are seen in relative prevalence amongst subtypes in YOD as compared to LOD [4].

Although YOD accounts for a relatively small number of cases compared to LOD, more knowledge about its epidemiology, economic and psychosocial consequences is needed. Obtaining this knowledge will result in further optimisation of our social and health care system, meanwhile improving the quality of life (QoL) of both patient and family.

Being diagnosed with dementia significantly changes the physical, psychosocial and financial situation of both patient and family. At the time of diagnosis, people with YOD are often still employed or financially responsible for their family and dependent children. The diagnosis could have a significant impact on educational performances of their children or reduce the family's ability of mortgage repayment. Awareness of the ongoing deterioration results in high levels of stress and increased risk of depression amongst patients.

Caregivers of persons with YOD show feelings of fear, risk of depression and often experience more difficulties in daily functioning compared to caregivers for the elderly [5]–[9].

The effects on multiple involved persons and various aspects of life, support the need for a holistic approach in YOD. Holistic caregiving includes providing appropriate psychosocial, financial and medical support; which eventually will decrease disease burden and improve the QoL of patient, family and caregiver [10].

2. EPIDEMIOLOGY

2.1 Prevalence of YOD in Flanders, Belgium

Correlating with the aging population trend, the total number of people living with dementia in all OECD countries is expected to rise from approximately 19 million today, to 40.9 million in 2050. Globally 152 million people will have dementia by 2050 [1], [11], [12]. There is much uncertainty about the prevalence of YOD specifically. Recent research [13], [14] in the United Kingdom estimates YOD accounts for approximately 6-9% of the total dementia cases, meaning the true prevalence may be 3 to 4 times higher as previously thought based on registry-studies (2.2%). Studies estimate a YOD prevalence of 81-98 per 100,000 people aged 45-64, compared to 54 per 100,000 in the age group of 30-64 years. However, large variations in YOD prevalence due to different inclusion criteria and YOD definitions are observed between studies [4], [15].

In 2015 the total number of people living with dementia (YOD included) in Belgium was estimated at 201 762, with approximately 122 161 living in Flanders. In 2018 this number rose to 131 818. If lifestyle and therapeutic approaches remain unchanged this number tends to increase to 183 150 by 2035 and even double by 2060 [2].

According to the Flemish Alzheimer League and the Flemish Expertise Centre on Dementia, the actual number of formally diagnosed persons with YOD in Flanders is 1800 [16], [17]. Demographic statistics indicate the total number of people with YOD may remain roughly constant in upcoming years due to a reduction of Flemish inhabitants aged between 30-64 years old [2], [18]. As mentioned large variations in estimations of prevalence are seen between different sources. As there is no central registry system collecting prevalence data, researchers are obligated to estimate the Belgian or Flemish dementia prevalence by using available data in similar populations.

2.2 Subtypes of Young-Onset Dementia

According to Harvey et al. the four most common subtypes of YOD are Alzheimer's disease (AD) (34%), vascular dementia (VD) (18%), frontotemporal dementia (FTD) (12%), alcohol related dementia (10%) and Lewy body dementia (LB) (7%). The remaining 19% is represented by various onsets such as Huntington's disease, multiple sclerosis, dementia in Parkinson's disease (PD) and "not otherwise specified" forms [4]. Although AD is the main etiology in both YOD and LOD (respectively roughly 34% and 62%), a relatively higher prevalence of non-AD subtypes is observed in YOD [14], [19].

Genes may have a larger contribution in the onset of some YOD subtypes as several neurodegenerative disorders, such as Huntington’s disease, are associated with genetic mutations [4], [20]. Extrapolated on the estimated number of 1800 people with YOD, there are approximately 612 patients with AD (34% of 1800), 324 patients with VD, 216 patients with FTD, 126 patients with LB, 180 patients with alcohol related YOD and 342 patients with various onsets such as PD and Huntington's disease living in Flanders. The large heterogeneity in prevalence results in a higher complexity for both diagnosis and appropriate dementia care.

2.3 Economic impact of dementia in Belgium

As most studies focus on LOD to estimate the impact of dementia on the health care system, the costs of YOD remain largely unknown. Currently there are no Flemish or Belgian studies reported that have evaluated the costs of YOD. In 2006 Schoenen et al. estimated the total dementia cost in Belgium at approximately EUR 2.175 billion per annum or EUR 210 per capita [21]. Based on the yearly changes in Belgian consumer price index from 2006 until 2019, these costs could be estimated at EUR 2.768 billion per annum or EUR 267 per capita in 2019 [22]. Despite the fact that this study gives an indication of the actual dementia costs in Belgium, it is important to mention only patients aged ≥ 65 were included.

The 1-year prospective Belgian National Dementia Economic Study (NADES) estimated the total monthly, per patient, cost for providing home and institutional care at respectively EUR 445 and EUR 2302. Out of the total costs for home care about 60% was being paid by the Belgian health care system, compared to 46% for institutional care. Similar to the previous study only LOD patients were included, meaning these costs can only serve as indicators. Additionally, these estimates may be outdated as the NADES study was implemented in 2002 [23]. Based on the yearly consumer price indices from 2002 until 2019; we could estimate the monthly, per patient, costs of home and institutional care in 2019 at EUR 614 and EUR 3179 respectively [22].

Costs of home care can be subdivided in non-medical (23%) and medical costs (77%). Medical costs include doctor visits, nursing, physiotherapy, hospitalisation and medication. Non-medical costs exist out of purchasing/renting equipment for home adaptations (e.g. hospital bed, alarms), services such as home delivery of meals, costs for professional help (e.g. housemaid, social worker) and costs associated with caregiving (e.g. transport and opportunity costs).

In home care, hospitalisation and medication are identified as the highest cost determinants for the health care system. Meanwhile medication, non-medical costs for the main caregiver and assistance for household tasks were identified as highest cost determinants for patient, family and caregiver.

In the case of institutional care, nursing cost was identified as highest cost determinant for the health care system; whereas residential cost was the highest determinant for patient/family and caregiver. As opposed to home care, institutional care costs for the health care system were markedly influenced by dementia severity (monthly EUR 211-288 for home care and EUR 329-1258 for institutional care) [23]. Based on yearly changes in consumer price index we could estimate these costs in 2019 at EUR 291-397 and EUR 454-1737 respectively [22]. Mean monthly costs for patient, family and caregiver are EUR 159-268 and EUR 1207-1331 for home and institutional care respectively [23]. Estimated ranges for 2019 are EUR 219-370 and EUR 1666-1838 respectively [22].

From an economic point of view, these results support providing home care instead of institutionalisation. However, these estimates are based on the LOD population and can only act as an indication for YOD costs. Actual YOD costs may differ significantly as YOD is associated with higher total and indirect costs compared to LOD. A prospective study by Kandiah et al. concluded median annual costs for community-dwelling persons with YOD were almost twice the cost of LOD. When subdivided by YOD aetiology FTD (highest cost), VD and AD show higher costs compared to the corresponding subtype in the elderly [24]. Denny et al. (USA, 2017) estimate the mean total annual per patient costs of FTD, in all age categories combined, at approximately USD 119 654. This can be subdivided in USD 47 916 direct and USD 71 737 indirect costs. Patients aged <65 years tend to show higher total (USD 11 950) and indirect costs compared to the population aged ≥65 years. Direct costs show a lower tendency in the population aged ≤65 years. Men show higher indirect costs as they are more likely to use unpaid care and to stop working. Meanwhile women are more likely to live in nursing homes/assisted living facilities, resulting in higher direct costs [25].

43% of the persons with YOD report loss of employment due to the diagnosis, compared to 2.4% in LOD [24]. In addition, informal caregivers often need to alter their careers in order to provide the needed care. The diagnosis of YOD may thus have substantial consequences on the financial stability of the affected families. The previous mentioned study by Denny et al. reports that being diagnosed with FTD, results in a mean decrease in household income from USD 75,000-99000 (one year before diagnosis) to USD 50 000-59 999 one year after diagnosis [25]. This study is not based on patients living in Flanders, but emphasises the significant financial consequences that go along with YOD.

3. Psychosocial impact of YOD

The lower prevalence and various presentations in early stage, such as depression and behavioural changes instead of cognitive decline, lead to the fact that YOD is more likely to be overseen in differential diagnoses [20]. Van Vliet et al. conclude that YOD is associated with an average of 4.4 years between symptom onset and diagnosis, compared to 2.8 years in LOD [26]. Timely diagnosis in YOD is important for both informal caregiver and patient in order to change their perspectives on the situation and to seek appropriate support.

Compared to people with LOD, a higher level of "dementia-awareness" is reported in people with YOD. Higher awareness is associated with depressive symptoms, a lower self-reported QoL and may consequently increase the risk of committing suicide [9], [27]–[29]. However, more studies are needed in order to identify the significance of risk factors such as "dementia subtype" and "awareness" [30] .

A study by Millenaar et al., based on proxy reports, indicates the presence of a positive relation between the patients' awareness and QoL. This can be partially explained by the fact that higher awareness could result in a more active role of the person with YOD in the decision-making of his/her own care planning. In this study a higher number of needs, either met or unmet, is associated with a lower QoL [31]. The association between number of unmet needs and lower patients' QoL is not seen in the study of Bakker et al. [32]. In both studies patients' and caregivers' needs were assessed by interviewing the caregivers. It is important to mention the potential differences between self and proxy reports in identifying the QoL of a person with YOD. Usage of proxy reports may lead to inadequate conclusions as the evaluations may be influenced by the caregivers' own burden, emotional state and attitude [33].

Although informal carers in LOD provide care for people with greater functional impairments and experience more burden, informal carers report significant poorer QoL in YOD compared to LOD. Lower QoL is characterised by concerns on dependency, fear and increased incidence of depression. One of the explanations of this poorer QoL could be the higher prevalence of FTD, which is associated with more behavioural changes and lower disease awareness as compared to AD [5], [7], [8], [34]. The number of unmet needs of both patients and caregivers is negatively related to the caregivers' QoL [32]. In the study of Denny et al. 67% of the FTD informal caregivers reported a notable decline in their health, 53% reported increased personal health care costs [25]. As YOD appears in a rather unexpected stage of life, YOD caregivers are less likely to be prepared for their caregiving role. Caregivers experience burden due to the internal strain of "willingness to care" and their own changing future perspectives. YOD caregivers still mention the lack of appropriate support and often feel uncomfortable sharing the diagnosis with others, which may result in social isolation [6], [35].

Next to the psychological distress, higher caregiver burden increases the desire and likelihood to institutionalise people with YOD [36]–[40].

Besides the known significant impact on the family, very few studies focus on how the diagnosis of YOD affects children or young adults as informal caregivers [41]. Acting as an informal caregiver in the young adulthood may have a positive influence on the personality development. However, caregiving at young age may also result in psychological distress (cfr. parentification) or negatively influence academic performances, leading to less accessibility of jobs associated with higher incomes [42], [43]. A survey amongst 12 681 public school students in the USA reports that academic performances are negatively influenced in 67.1% of the young caregivers [44]. The fact that YOD affects patients, spouses, dependent children and other relatives at various aspects of life, emphasises the need for holistic caregiving. Holistic caregiving includes providing support on medical, financial and psychosocial consequences that go along with the diagnosis [45].

4. Flemish initiatives focusing on YOD specifically

Currently the Flemish Expertise Centre on Dementia, the Regional Expertise Centre "Memo" and other partners released the website "www.jongdementie.info", literally translated as “www.youngonsetdementia.info”, offering pertinent information concerning dementia diagnosis and available allowances [46].

In 2015, the criteria for the institutionalisation of people aged younger than 65 in care homes were made more flexible by the Flemish Government. Previously, the number of inhabitants younger than 65 years in residential centres was limited to 10% of the total number. A special request was needed for every additional user.

Residential care facilities are now allowed to care for a group of users younger than 65 years on the condition that they have shared care and support needs, even if this means the limit of 10% will be exceeded. Day-care centres, that exclusively provide care and services to users with a specific chronic condition, are not subjected to age restrictions. Other day-care centres have a restriction of maximum 25% users aged 65 or less [18].

The sudden need for institutionalisation at young age can be an extra financial burden for relatives or may be a reason why people postpone extra support for the person with YOD. Unpublished data from Roos et al. estimates current institutional costs for patient/family in Flanders at EUR 1950 per month (which is in line with our estimated cost range of EUR 1666-1838). This results in an extra annual cost of EUR 23 400, which can have a major impact on the financial stability of patients and family. The Flemish Government foresees an extra annual budget of EUR 3 million from 2019 onwards, in order to support people with YOD who need institutionalisation. The budget includes a daily allowance of EUR 25 for 203 patients and extra operating funds. Other extra subsidies for selected long-term care facilities with a specialisation in care and support for patients with YOD are foreseen [47].

4.1 Local initiatives

In 2017 vzw Woonzorgnet-Dijleland (a non-profit organisation existing out of 4 local long-term care facilities in the province of Flemish-Brabant), the Regional Expertise Centre on Dementia "Memo" and several other partners implemented "Zorgcirkels Jongdementie”, literally translated as “Care circles YOD”. YOD patients, together with professionals, are active members of the board and based on their input holistic, patient-centred care is pursued.

Through the implementation of eight circles, the initiative tries to guide patient and family from diagnosis until end-of-life. The circles exist out of: (1) the development of a strong first-line care, (2) personal guidance by an appointed mentor, (3) meeting homes, (4) day-care, (5) co-housing, (6) volunteering buddy’s, (7) education and (8) meeting. At “the meeting home” patients and family can receive all the needed information or ask for personal guidance from the appointed mentor. This guidance may include advice concerning the available allowances or the offering of psycho-educational programmes for informal carers [48].

Similar initiatives are implemented by other local dementia expertise centres. By instance, the "Foton Expertise Centre" in the city centre of Bruges (province of West-Flanders) opened a similar "meeting home" where patients and family can receive necessary information, socialise with others or receive psychosocial support. If needed, day-care or short-term stays can also be made possible [49]. "Het Ventiel", also located in West-Flanders, organises weekly activities and guides more than 50 persons with YOD in the region [50].

5. Recommendations for scaling and diffusion of innovations

Based on the information summarised in this report, we formulate several recommendations for future policy making.

Firstly, we emphasise the further need of providing patient-centred guidance and the further stimulation of new projects, like “Zorgcirkels” throughout all of Flanders and other regions in the world. The implementation of a holistic approach in care paths is needed as informal carers and persons with YOD have significantly different needs as compared to LOD.

Next to medical support, patients with YOD need to receive appropriate psychosocial and financial support. Initiatives on a local level, such as "meeting homes", provide the needed local psychosocial and financial guidance along with the formal caregivers. Stronger interdisciplinary cooperation could lead to a synergic improvement of the patients' and informal carers' QoL by a reduction of the psychological burden. Research by LUCAS, the KU Leuven Centre for Care Research and Consultancy, supports local and person-centred initiatives like “Zorgcirkels” as they provide psychosocial and practical support for both patient and informal carer. Informal carers, associated with “Zorgcirkels”, show high satisfaction as they feel informed and supported on how to provide high-quality care for the person with YOD. Next to this, the organisation “Zorgcirkels” allows informal carers and patients to extend their social network [51].

Secondly, we ask policy makers to further pursue an implementation of memory clinics with special attention for YOD and a further streamlining of the diagnostic pathway. YOD-memory clinics could act as specialised centers with more experience in the field of YOD diagnoses and provide crisis-management when needed. As mentioned earlier, persons with YOD have significant additional needs compared to persons with LOD, meaning there is an inherent risk that these needs will not be addressed by general dementia services. Further diagnostic streamlining is also part of the “Ten-Point Action Plan” formulated by the workgroup YOD Flanders [46].

Thirdly, we aim for further support of community-dwelling persons with YOD. The current allowance of EUR 3 million will only partially meet the needs of persons with YOD, more specifically people who need long-term institutionalisation.

In order to further support patients at home, a case-manager/liaison is needed. Current guidelines, in the context of LOD, recommend the appointment a central coordinating person during the caregiving process.

As no criteria are formulated for this role, this can be assigned to nurses, social workers, GPs or informal carers. We ask policy makers to further stimulate the appointment of a case-manager who will be able to frequently evaluate the needs of the patient and family [47], [52], [53].

Fourthly, we recommend policy makers to continue dialogue for dementia awareness amongst professionals and citizens. More awareness about dementia in general, YOD and its various symptoms is needed in order to provide a “timely diagnosis”, reduce stigma and improve the patients’ and caregivers' QoL. At this moment professional caregivers can follow a dementia training in order to become a "dementia reference person" accredited by the Federal Public Health Service. This reference person, who will be in close contact with experts from dementia expertise centres, can give advice to other professionals handling fewer cases. In order to support local pharmacists, the Expertise Centre and the Flemish Pharmacists’ Network developed supporting tools which are summarised and offered in a binder called “Farmaceutische zorg voor personen met dementie” (FAZODEM), literally translated as “Pharmaceutical care for people with dementia”. These initiatives are mainly focusing on LOD, but must also inform on the specificities of YOD [17], [18], [54]. Ethical communication that raises dementia awareness amongst citizens could further reduce the psychological barrier and stigma that limits opportunities for talking about dementia. Communication can activate citizen engagement including the potential increase for the number of volunteers as “buddy’s.” This engagement is needed in order to pursue holistic caregiving. Some examples on how to increment awareness amongst citizens are campaigns such as “Forget dementia, remember the person” by the Expertise Centre. Through animation movies, cartoons and a dynamic web platform, the campaign aims to reduce stereotypes, stimulate interaction between formal and informal caregivers and emphasises the importance of respectful language towards the patient [17], [55], [56].

In order to reach a broader public, these campaigns could be implemented as part of broad public education including in school curricula. As Flanders has a somewhat diverse population, in 2017 8.5% of the Flemish inhabitants had a different ethnic-cultural background, the implementation of “dementia” in school curricula could be efficient in order to reach all families and to develop a “dementia literacy” amongst citizens [18], [57].

Finally, we emphasise the need of a centralised electronic registry system in order to collect high quality prevalence data of dementia in general and YOD specifically. According to the OECD less than 40% of all OECD countries can estimate diagnosis rates of dementia on a national level [39]. A first step in gaining more qualitative data is made through the implementation of "VIVEL" or "Vlaams Instituut Voor de Eerste Lijn", literally translated as “Flemish Institute for First-line Care”, in 2019. Next to the collection of data, this organisation will also provide coaching for the first-line care [58]. More accurate data is needed in order to develop and implement efficient policies throughout society; and to conduct high-quality economic studies such as a comparison of the potential economic advantages of holistic caregiving compared to early institutionalisation. These economic studies could further demonstrate the added value of local patient-centered care.

6. CONCLUSION

This article summarises the actual prevalence of dementia and its subtypes in Flanders, Belgium. The current number of patients with dementia in Flanders is estimated at 131 818 and will likely increase to 183 150 by 2035. Among this group roughly 5461 people have Young-Onset Dementia (YOD), from which approximately 1800 persons carry the formal diagnosis.

In 2006 dementia in Belgium accounted for an annual cost of approximately EUR 2.175 billion or roughly EUR 210 per capita (estimations based on changes in consumer price index are respectively EUR 2.768 billion and EUR 267 for 2019). This estimate excludes patients aged younger than 65, making actual costs of dementia even higher. YOD is associated with higher total and indirect costs as compared to Late-Onset Dementia (LOD). Especially frontotemporal dementia shows a substantial economic burden. This article emphasises the higher "dementia-awareness" amongst YOD patients, the significant impact on quality of life (QoL) of spouses/informal carers and the various effects on financial and psychosocial wellbeing. The earlier onset of YOD compared to LOD makes the impact significantly different from each other.

Currently, several initiatives are implemented in order to further improve the patients’ and carers’ QoL. As such, a website specifically focusing on YOD is released and local initiatives as "Zorgcirkels Jongdementie" try to provide the needed holistic approach. Holistic caregiving includes guidance of patient and family throughout the whole care process, with attention for medical, psychosocial and financial needs. Several recommendations are given for further scaling and diffusion of innovations.

In general, we recommend policymakers to further support person-centred initiatives like Zorgcirkels, to pursue the development of memory clinics specialised in YOD diagnosis and care, to further stimulate the appointment of a case-manager/liaison, to raise dementia awareness with ongoing communication amongst professionals and citizens; and lastly, to pursue the implementation of a dementia-registry system.

7. DECLARATIONS

7.1 Conflicts of interest

None

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