

## Article

# Higher prevalence of dementia but no improvement in total comfort while dying among nursing home residents with dementia between 2010 and 2015: Results from two retrospective epidemiological studies

Rose Miranda <sup>1,2</sup>, Tinne Smets <sup>1,2</sup>, Nele Van Den Noortgate <sup>3</sup>, Luc Deliens <sup>1,2,4</sup>, and Lieve Van den Block <sup>1,2</sup>

<sup>1</sup> End-of-Life Care Research Group, Vrije Universiteit Brussel (VUB) and Ghent University, 1090 Brussels, Belgium; [rose.miranda@vub.be](mailto:rose.miranda@vub.be) (R.M.) [tinne.smets@vub.be](mailto:tinne.smets@vub.be) (T.S.); [lin.deliens@vub.be](mailto:lin.deliens@vub.be) (L.D.); [lieve.van.den.block@vub.be](mailto:lieve.van.den.block@vub.be) (L.V.D.B.)

<sup>2</sup> Department of Family Medicine and Chronic Care, Vrije Universiteit Brussel (VUB), 1090 Brussels, Belgium

<sup>3</sup> Department of Geriatric Medicine, Ghent University Hospital, 9000 Ghent, Belgium; [nele.vanden-noortgate@uzgent.be](mailto:nele.vanden-noortgate@uzgent.be)

<sup>4</sup> Department of Public Health and Primary Care, Ghent University Hospital, 9000 Ghent, Belgium

\* Correspondence: [rose.miranda@vub.be](mailto:rose.miranda@vub.be) (R.M.)

**Abstract:** Important policy developments in dementia and palliative care in nursing homes between 2010 and 2015 in Flanders, Belgium might have influenced which people die in nursing homes and how they die. We aimed to examine differences between 2010 and 2015 in the prevalence and characteristics of residents with dementia in nursing homes in Flanders, and their palliative care service use and comfort in the last week of life. We used two retrospective epidemiological studies, including 198 residents in 2010 and 183 in 2015, who died with dementia in representative samples of nursing homes in Flanders. We found a 23%-point increase in dementia prevalence ( $P\text{-value}<0.001$ ), with a total of 11%-point decrease in severe to very severe cognitive impairment ( $P=0.04$ ). Controlling for this difference in resident characteristics, in the last week of life, there were increases in the use of pain assessment (+20%-point;  $P<0.001$ ) and assistance with eating and drinking (+10%-point;  $P=0.02$ ) but no change in total comfort. The higher prevalence of dementia in nursing homes with no improvement in residents' total comfort while dying emphasize an urgent need to better support nursing homes in improving their capacities to provide timely and high-quality palliative care services to more residents dying with dementia.

**Keywords:** Long-term care, care homes, nursing homes, dementia, quality improvement, palliative care

## 1. Introduction

Over the past decade, there have been important policy developments related to dementia and palliative care in the nursing home sector in many countries, which might have influenced which people die in nursing homes and how they die, and can impact the provision of palliative care for nursing home residents with dementia.[1,2] Yet, there is a lack of high-quality data on the number of residents dying in nursing homes with varying stages of dementia, the extent to which palliative care services are used, and how these are changing over time. In this study, we will examine differences between 2010 and 2015 in the prevalence and characteristics of residents with dementia in nursing homes in

Flanders, the Dutch-speaking part of Belgium where about 60% of the population live,[3] as well as differences in their palliative care service use and comfort in the last week of life.

Between 2010 and 2015, new dementia policies in Flanders were oriented towards delaying the institutionalization of older people with dementia by enabling them to stay at home for as long as possible.[4-8] Several initiatives for people with dementia living in communities were also implemented regionwide, e.g. information campaigns and trainings of primary care professionals and family caregivers.[9-12] While these developments could potentially result in fewer admissions or shorter stay in nursing homes or more admissions of those with advanced conditions unmanageable at home,[13,14] representative data showing these potential changes are lacking.

Particularly three developments related to palliative care in the nursing home sector in Flanders are historically important. First, supported by the 2002 Belgian Palliative Care Law that recognizes the legal right to palliative care of 'patients whose life-threatening illness no longer responds to curative treatments',[15] the Flemish government passed the Decree on Residential Care in 2009.[16] This decree officially requires Flemish nursing homes to support, sensitize and train all regular staff regarding palliative care. Second, in 2010, the Flanders' Federation of Palliative Care launched palliative care guidelines for professional caregivers in nursing homes in developing and implementing palliative care in their facility,[17,18] including the comprehensive delivery of physical, psychosocial and spiritual support.[18] Third, in 2013, the Flemish government introduced a strategy to evaluate quality of care in nursing homes by having them report on 13 quality indicators.[19] Two of these quality indicators concern palliative care ('place of death' and 'advance care planning'). These indicators are used to systematically monitor the aggregate quality of care in this sector and to identify areas where improvements can be made. Despite these policy developments for nursing homes, no epidemiological study has yet examined the use of palliative care services of residents with dementia and their comfort while dying before and after these developments. Examining this will inform policymakers in Belgium on how to further improve the quality of care at the end of life of nursing home residents with dementia. Results can also be used to inform policies in many countries, especially in Western Europe with similar shifts in health care policies.[1,2] Hence, focusing on Flanders, we sought to answer the following research questions:

- Are there differences in the prevalence of dementia in nursing homes between 2010 and 2015?
- Are there differences in the socio-demographic and clinical characteristics of nursing home residents with dementia between 2010 and 2015?
- Are there differences in palliative care service use and comfort in the last week of life of nursing home residents with dementia between 2010 and 2015?

## 2. Materials and Methods

### 2.1. Design

We used data from two retrospective epidemiological studies in regionwide representative samples of nursing homes in Flanders, Belgium, namely the Dying Well with Dementia study focused on residents with dementia (2010) and the PACE study

focused on all residents, of whom the presence of dementia was determined (2015).[20,21] Both studies used similar research methods, unless otherwise indicated.

### *2.2. Participating nursing homes*

To obtain regionwide representative samples of nursing homes, proportional stratified random sampling methods. From a national list, the research team randomly sampled Flemish nursing homes, stratified by region (five provinces), bed capacity (up to or more than 90 beds), and ownership (public, private/non-profit, private/profit). If a nursing home refused to participate, another one was randomly selected from the same stratum until the targeted number per stratum was reached.[20,21]

### *2.3. Data collection and study population*

The administrator/manager in each nursing home was asked to identify all residents who died in the previous three months. Because the 2010 study focused on dementia, the residents who did not have dementia were excluded immediately before data collection. This was done by asking the administrators/managers to further identify residents who met the Katz scale criteria used by the Belgian health insurance system to allocate financial resources: “category Cdementia”, i.e. being completely care dependent or needing help for bathing, dressing, eating, toileting, continence and transferring plus being disoriented in time and space OR “disorientation in time and space” ( $\geq 3$  or “almost daily a problem with disorientation in time and space”).[20,21]

In 2010, data were collected on residents who met at any of the Katz scale criteria, while in 2015, data were collected on all identified residents. To collect data, both studies used after-death questionnaires distributed to nursing home staff most closely involved in care, GP and nursing home administrator. Dementia was determined by asking the GP and the nursing home staff if the resident “had dementia” or “was diagnosed with dementia”. Dementia was present if the nursing home staff and/or the GP indicated it, and no dementia when both respondents indicated it; or when one indicated it, but the other did not return the questionnaire or did not answer the question.[20,21]

Response rates for staff, GPs and administrators were respectively 88.4%, 52.9% and 95.0% in 2010 and 85.1%, 68.3% and 94.2% in 2015. We excluded residents for whom the nursing home staff did not return the questionnaire. Non-response analysis showed no difference in residents’ characteristics between cases for whom the questionnaire was returned by nursing home staff or not.[20,22]

### *2.4. Measurements*

Using validated instruments, the nursing home staff reported residents’ cognitive and functional impairment one month before death. Cognitive Performance Scale (CPS) uses five variables from the Minimum Data Set to group residents into six hierarchical cognitive performance categories, e.g. CPS scores 5-6 indicate severe and very severe impairment.[23] Global Deterioration Scale (GDS) is divided into seven stages, of which stage 7 indicates that a resident lost all verbal abilities, was incontinent/required assistance with eating and toileting, and lost basic psychomotor skills.[24] To compare with earlier studies,[20,22] we

determined severity of dementia using CPS and GDS (CPS scores $\geq$ 5 and GDS stage=7 had advanced dementia, while the rest had non-advanced dementia). The nursing home staff also reported Bedford Alzheimer Nursing Severity scale (BANS-S), with total scores ranging from 7 (no impairment) to 28 (complete impairment).[25] They also reported whether any clinical complication occurred in the last month of life, e.g. pneumonia or intake problems. The GPs reported co-existing conditions, e.g. cancer or cardiovascular disease. Nursing home administrators reported residents' age at time of death, gender, length of stay in nursing homes, place of death, and whether the residents stayed in an open or secured unit at the time of death and in a dementia care unit or not.

The nursing home staff reported data on palliative care service use, including 1) whether a palliative care record was initiated for residents and the days before death when this occurred; 2) whether a resident received palliative care at any time, including whether this palliative care was provided by a GP and whether the following persons/initiatives were involved in providing this care: coordinating and advisory physician, palliative care reference nurse, palliative care task group, specialist palliative home care team, or none of them. Since 2009, nursing homes in Flanders were officially required to establish a functional relationship with a general practitioners (GPs) responsible for providing medical care and developing palliative care strategies for residents; and coordinating and advisory physicians responsible for coordinating with GPs to review palliative care strategies and give advice and training to staff.[16,26] Further, the nursing homes must have a palliative care reference nurse responsible for establishing a supportive palliative care culture and awareness within the nursing home, training personnel regarding palliative care, and supporting and coordinating palliative care delivery; and a palliative care task group comprising of all palliative caregivers. For complex palliative situations, palliative home care teams can either call or visit nursing homes to provide advice or support.[16,26] The nursing home staff also reported whether the residents received services related to medical or nursing treatments/procedures in the last week of life, psychosocial interventions in the last month and spiritual and/or pastoral care before death. They also assessed comfort in the last week of life using Comfort Assessment in Dying-End-of-Life in Dementia (CAD-EOLD) scale. CAD-EOLD is a validated 14-item scale comprising discomfort, pain, restlessness, shortness of breath, choking, gurgling, difficulty swallowing, fear, anxiety, crying, moaning, serenity, peace and calm. Individual item scores range from 0-3, while total scores range from 14 to 42, with higher scores representing better comfort.[27,28]

### 2.5. Data analyses

The 2010 and 2015 databases were merged by RM and two palliative care researchers. The prevalence of dementia between 2010 and 2015 were compared using  $\chi^2$ -test. Subsequent analyses were performed in IBM SPSS statistics version 26 (©IBM Corporation) using generalised linear mixed model to account for clustering of data within nursing homes. We compared residents' characteristics and their palliative care service use and comfort scores between 2010 and 2015. We adjusted all analyses for resident characteristics

that differed between the years. Hypothesis testing was two-sided. Statistical significance was set at  $P<0.05$ .

### 3. Results

#### 3.1. *Prevalence of dementia*

The prevalence of dementia significantly increased from 45% in 2010 (205 of 458 residents) to 68% in 2015 (199 of 291 residents) (+23%-point;  $P$ -value<0.001; Figure 1). Of the residents with dementia, we excluded 7 residents in 2010 and 16 in 2015, as the nursing home staff did not return the questionnaires, leaving 198 and 183 residents for further analyses.

#### 3.2. *Characteristics of residents with dementia*

Between 2010 and 2015, residents' characteristics did not change, except for scores on the Cognitive Performance Scale. One month before death, the proportion of residents with dementia with severe to very severe cognitive impairment (CPS scores 5-6) had a total of 11%-point decrease ( $P=0.04$ ; Table 1). The residents were about 86 years of age at the time of death, were predominantly women, and had BANS-S scores of 20.9 in 2010 and 20.3 in 2015. Of the residents in 2010 and 2015 respectively, 49% and 52% had advanced dementia, while 95% and 92% experienced any clinical complication a month before death. The most common co-existing conditions were cardiovascular diseases (29% in 2010 and 28% in 2015), followed by cancer and respiratory conditions. The median length of stay in nursing homes was 893 days in 2010 and 688 days in 2015. In 2010 and 2015 respectively, nursing home was the most common place of death (90% and 86%), while 9% and 14% died in hospitals.

#### 3.3. *Palliative care service use among residents with dementia*

In multivariable analyses controlled for differences in CPS scores, in 2010 and 2015 respectively, a palliative care record was initiated for 62% and 72% of residents ( $P=0.052$ ), of which 51% and 60% occurred within 14 days before death ( $P=0.28$ ; Table 2). According to nursing home staff, 83% in 2010 and 82% in 2015 of residents received palliative care. For 17% (2010) and 20% (2015) of these people who received palliative care, no coordinating and advisory physician, palliative care reference nurse, palliative care task group and palliative home care teams were involved ( $P=0.30$ ).

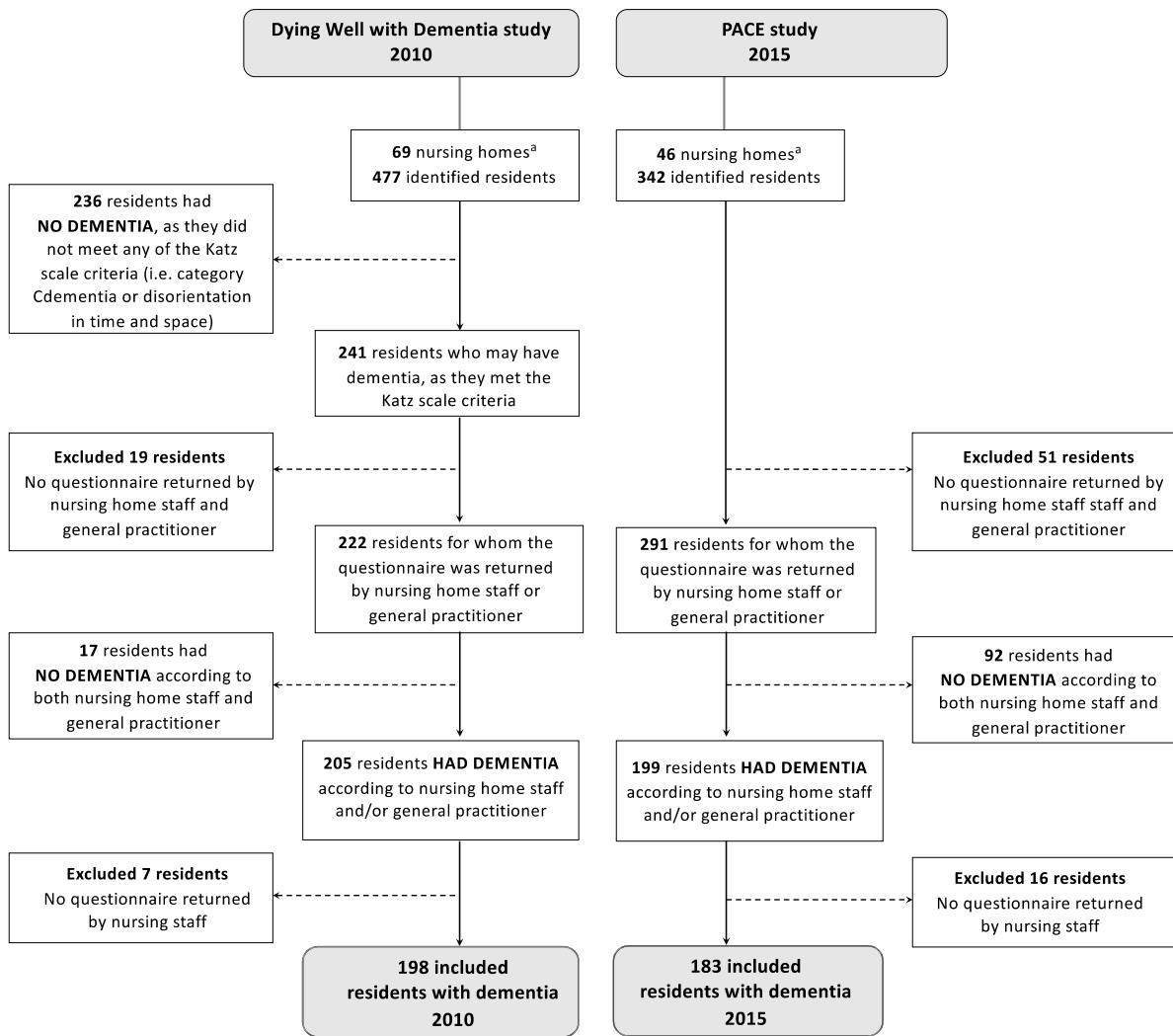
In the last week of life, there were significant increases in the percentages of residents for whom pain assessment was conducted (from 63% in 2010 to 83% in 2015;  $P<0.001$ ) and who received assistance with eating and drinking (from 72% in 2010 to 82% in 2015;  $P=0.02$ ). In the last month of life, the percentage of residents for whom their environment was adjusted, e.g. to promote walking around safely, increased from 10% in 2010 to 16% in 2015 ( $P=0.03$ ), while 37% (2010) and 47% (2015) of residents did not receive any psychosocial intervention ( $P=0.22$ ). In 2010 and 2015 respectively, shortly before death, 48% and 57% of residents received spiritual care, meaning that 52% and 43% did not receive it ( $P=0.06$ ).

#### 3.4. *Comfort in the last week of life*

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A week before death, there were 0.2-point increases in the comfort scores related to pain ( $P=0.04$ ) and moaning ( $P=0.03$ ) and fear ( $P=0.046$ ) and (Table 3). The estimated marginal means for the total comfort scores did not change between 2010 (30.0; 95% CI=29.2-30.8) and 2015 (30.8; 29.2-30.9;  $P=0.39$ ).

### 3.2. Figures, Tables and Schemes



**Figure 1. Overview of the identification of residents with dementia in 2010 and 2015**

<sup>a</sup> Because we excluded a number of residents from the total sample, the final number of nursing homes were 64 in 2010 and 43 in 2015.

<sup>b</sup> In 2010, 205 residents had dementia, while 253 residents had no dementia (236 residents did not meet the Katz scale criteria and 17 had no dementia according to both the nursing home staff and general practitioner) (N=458). In 2015, 199 residents had dementia, while 92 residents had no dementia according to both the nursing home staff and general practitioner (N=291).

Table 1. Comparing residents' characteristics between 2010 and 2015

RESIDENTS' CHARACTERISTICS	2010 (N=198)	2015 (N=183)	Change	Difference be- tween the years P-values <sup>†</sup>
<b>Socio-demographic characteristics</b>				
<b>Age at time of death, average in years (SD)</b>	86.7 (7)	86.9 (7.3)	+0.2	0.73
<b>Gender, female n (%)</b>	115 (61)	114 (65)	+4	0.43
<b>Clinical characteristics</b>				
<b>Cognitive performance scale (CPS), n (%)</b>				<b>0.04</b>
- Intact, borderline intact, mild impairment (score 0-1-2)	8 (4)	21 (13)	+9	
- Moderate impairment (score 3)	27 (14)	20 (12)	-2	
- Moderately severe impairment (score 4)	9 (5)	15 (9)	+4	
- Severe impairment (score 5)	61 (33)	52 (31)	-2	
- Very severe impairment (score 6)	82 (44)	58 (35)	-9	
<b>Bedford Alzheimer Nursing Severity scale (BANS-S) 1 month before death, mean (SD)</b>	20.9 (3.9)	20.3 (4.3)	-0.6	0.19
<b>Severity of dementia, n (%)</b>				0.55
- Non-advanced dementia	95 (51)	75 (48)	-3	
- Advanced dementia	92 (49)	82 (52)	+3	
<b>Occurrence of clinical complications in last month of life, n (%)</b>	179 (95)	168 (92)	-3	0.31
<b>Co-existing conditions</b>				
- Cancer	12 (11)	19 (14)	+3	0.43
- Cardiovascular	32 (29)	37 (28)	-1	0.89
- Respiratory	15 (14)	14 (11)	-3	0.51
- Neurological (not dementia)	17 (15)	10 (8)	-7	0.08
- Urogenital	9 (8)	12 (9)	+1	0.82
- Other	18 (16)	22 (17)	+1	0.99
<b>Length of stay in nursing home in days, median days (IQR)</b>	893 (448-1694)	688 (283-1678)	-205	0.28
<b>Place of death, n (%)</b>				0.20
- Nursing homes	171 (90)	152 (86)	-4	
- Hospital	17 (9)	24 (14)	+5	
- Other <sup>‡</sup>	2 (1)	0 (0)	-1	
<b>Type of unit at time of death, n (%)</b>				0.71
- Open unit	91 (48)	88 (50)	+2	
- Secured unit	98 (51)	88 (50)	-1	
<b>Dementia care unit, yes, n (%)</b>	99 (53)	93 (53)	0	0.95

SD=standard deviations; IQR=Interquartile range; GLMM=generalized linear mixed model analyses.

† Calculated using GLMM to account for correlation of data within nursing homes; 'other' categories not included in calculation of *P*-values. Because the CPS scores differed between the years, further analyses were adjusted for CPS.

‡ Examples of places of death other than nursing homes or hospitals include facility hospice/palliative care unit.

§ Nurse most involved in care included registered nurse, head nurse/matron and reference nurse.

Missing values, n: age, 2010=12; 2015=8 | gender, 2010=11; 2015=9 | severity of dementia, 2010=11; 2015=26 | CPS, 2010=11 ; 2015=17 | GDS, 2010=16; 2015=12 | BANS-S, 2010=4; 2015=2 | clinical complications, 2010=10; 2015=15 | all co-existing conditions except other, 2010=87; 2015=51 | other co-existing conditions, 2010=88; 2015=51 | length of stay in nursing homes, 2010=13; 2015=10 | place of death, 2010=10; 2015=7 | type of unit, 2010=9; 2015=7 | dementia care unit, 2010=10; 2015=8.

Table 2. Comparing palliative care service use between 2010 and 2015

PALLIATIVE CARE SERVICE USE	2010	2015	%-point	Difference between years	
	(N=198)	(N=183)		Crude	Adjusted
n (%)	n (%)	change <sup>†</sup>	(P-values <sup>‡</sup> )		
<b>Residents who had a palliative care record</b>	121 (62)	97 (72)	+10	0.10	0.052
Time before death when the palliative care record initiated					
-< 14 days	51 (51)	38 (60)	+9	0.10	0.28
-15 to 90 days	32 (32)	22 (35)	+3		
-> 90 days	18 (18)	3 (5)	-13		
<b>Residents who received palliative care at any time according to nursing home staff</b>	162 (83)	145 (82)	-1	0.69	0.91
Palliative care was provided by GP	136 (84)	123 (86)	+2	0.84	0.87
Other person/initiatives involved in providing the palliative care					
- Coordinating and advisory physician	44 (27)	35 (23)	-4	0.44	0.43
- Palliative care reference nurse	110 (66)	94 (62)	-4	0.64	0.60
- Palliative care task group within the nursing home	81 (49)	64 (42)	-7	0.35	0.56
- Palliative home care teams (external)	16 (10)	8 (5)	-5	0.24	0.22
- No one from this list was involved	28 (17)	30 (20)	+3	0.55	0.30
<b>Residents who received medical or nursing treatments/procedures during the last week of life</b>					
Mouthcare	159 (80)	152 (88)	+8	0.055	0.059
Pain assessment	124 (63)	143 (83)	+20	<b>0.001</b>	<b>&lt;0.001</b>
Prevention of pressure ulcers	162 (82)	151 (87)	+5	0.15	0.10
Wound care	45 (23)	48 (28)	+5	0.27	0.29
Assistance with eating/drinking	142 (72)	141 (82)	+10	<b>0.04</b>	<b>0.02</b>
<b>Residents who received psychosocial interventions in the last month of life</b>					
Adjustments of environmental factors <sup>¶</sup>	19 (10)	28 (16)	+6	0.10	<b>0.03</b>
Activity programmes	25 (13)	16 (9)	-4	0.33	0.29
Music therapy	48 (24)	28 (16)	-8	0.17	0.15
Behavioural therapy	0 (0)	1 (1)	+1	0.87	0.90
Experiential approaches <sup>#</sup>	52 (26)	47 (28)	+2	0.90	0.73
No psychosocial interventions received	74 (37)	81 (47)	+10	0.15	0.22
<b>Residents who received spiritual and/or pastoral care shortly before death</b>					
Spiritual care provider/Pastoral worker	98 (48)	72 (57)	+9	0.10	0.06

GLMM=generalized linear mixed model; GP=general practitioners; pp=percentage point.

Crude model is the unadjusted model. Adjusted model is adjusted for difference in Cognitive Performance Scale (CPS) scores.

<sup>†</sup> %-point=percentage point. %-point difference was calculated between 2010 and 2015.

‡ Calculated using GLMM analyses to account for correlation of data within nursing homes.

§ Calculated using GLMM analyses to account for correlation of data within nursing homes while accounting for differences in resident characteristics; 'other' categories not included in calculation of *P*-values.

¶ Example of adjustments of environmental factors include modified environment for walking around safely.

# Examples of experiential approaches include multisensory environment, validation therapy.

Missing values, n: palliative care record, 2010=2; 2015=49 | receipt of palliative care, 2010=4; 2015=6 | palliative care provided by GP, 2010=5; 2015=9 | time before death when palliative care record was started, 2010=22; 2015=34 | all physical care, 2015=10 | all psychosocial care, 2015=12 | spiritual care, 2010=10; 2015=15.

**Table 3. Comparing comfort in the last week of life between 2010 and 2015**

COMFORT IN THE LAST WEEK OF LIFE	2010	2015	Score-point	Difference between years (P-values <sup>‡</sup> )	
	(N=198)	(N=183)	change <sup>†</sup>	Crude	Adjusted
				Crude	Adjusted
- Discomfort	2.1 (2.0-2.2)	2.1 (2.0-2.2)	-	0.46	0.58
- Pain	2.0 (1.9-2.1)	2.2 (2.1-2.3)	+0.2	<b>0.03</b>	<b>0.04</b>
- Restlessness	2.1 (2.0-2.2)	2.1 (2.0-2.2)	-	0.72	0.68
- Shortness of breath	2.2 (2.1-2.3)	2.4 (2.3-2.5)	+0.2	<b>0.03</b>	0.06
- Choking	2.1 (2.0-2.2)	2.1 (2.0-2.2)	-	0.77	0.52
- Gurgling	2.3 (2.2-2.4)	2.5 (2.3-2.6)	+0.2	0.13	0.23
- Difficulty swallowing	1.9 (1.8-2.0)	1.9 (1.8-2.0)	-	0.61	0.37
- Fear	2.0 (1.9-2.2)	2.2 (2.1-2.3)	+0.2	<b>0.04</b>	<b>0.046</b>
- Anxiety	2.1 (2.1-2.3)	2.2 (2.1-2.3)	+0.1	0.32	0.21
- Crying	2.7 (2.6-2.8)	2.7 (2.6-2.8)	-	0.49	0.77
- Moaning	2.3 (2.3-2.4)	2.5 (2.4-2.6)	+0.2	<b>0.02</b>	<b>0.03</b>
- Serenity	2.0 (1.9-2.2)	2.1 (2.0-2.2)	+0.1	0.69	0.27
- Peace	2.0 (1.9-2.1)	2.0 (1.9-2.2)	-	0.63	0.49
- Calm	2.0 (1.9-2.1)	2.0-1.9-2.1)	-	0.33	0.21
<b>Total score<sup>¶</sup>, estimated marginal means (95% CI)</b>	30.0 (29.2-30.8)	30.8 (29.2-30.9)	+0.8	0.22	0.39

CAD-EOLD=Comfort Assessment in Dying – End of Life in Dementia; CI=confidence intervals.

Crude model is the unadjusted model. Adjusted model is adjusted for difference in Cognitive Performance Scale (CPS) scores.

<sup>†</sup> Score point change was calculated between 2010 and 2015.

<sup>‡</sup> Calculated using GLMM analyses to account for correlation of data within NHs.

<sup>§</sup> Calculated using GLMM analyses to account for correlation of data within NHs while accounting for differences in resident characteristics.

<sup>¶</sup> Total scores are averages per whole scale multiplied by total number of items (i.e. 14). Cases with missing values on more than 25% of items per scale were excluded from total score calculation; scores range from 14 to 42; higher scores indicate better comfort when dying.

Missing values, n: discomfort, 2010=19; 2015=12 | pain, 2010=9; 2015=10 | restlessness, 2010=15; 2015=10 | shortness of breath, 2010=12; 2015=10 | choking, 2010=16; 2015=9 | gurgling, 2010=18; 2015=11 | difficulty swallowing, 2010=11; 2015=11 | fear, 2010=13; 2015=10 | anxiety, 2010=14; 2015=10 | crying, 2010=17; 2015=10 | moaning, 2010=16; 2015=9 | serenity, 2010=16; 2015=12 | peace, 2010=18; 2015=12 | calm, 2010=19; 2015=12 | total score, 2010=16; 2015=10.

#### 4. Discussion

Our study showed that between 2010 and 2015 in nursing homes in Flanders, Belgium, there was a 23%-point increase in the prevalence of dementia. Residents' characteristics did not change, except for the level of cognitive impairment in the last month of life, with a total of 11%-point decrease in residents with severe and very severe cognitive impairment. Pain assessment and assistance with eating and drinking in the last week of life were performed proportionally more often for residents in 2015 than in 2010. However, in both years, between 37% and 52% of residents neither received psychosocial intervention in the last month of life nor spiritual care shortly before death. In the last week of life, we found no change in residents' total comfort in the last week of life.

This is the first time that two retrospective epidemiological studies are used to investigate changes over time for residents with dementia in the context of important developments in the landscape of dementia and palliative care policies and initiatives in nursing homes.

Retrospective data collection is a feasible method for population-based epidemiological end-of-life studies, as it limits potential bias in prospective sampling, e.g. underrepresentation of people who live longer than the follow-up period.[22] Although these are separate studies, both utilised similar study designs, aiming to reach representative samples, and all variables of interest were measured in the same way. Finally, while the measurement of palliative care services is limited to services measured in both studies, these services comprise important components of palliative care in dementia, e.g. comprehensive delivery of physical, psychosocial, or spiritual support.[29] However, this study also has limitations. Because data were collected after death, there might be some recall bias.[22] Further, only the 2010 Dying Well with Dementia study used the Katz-scale criteria to exclude residents without dementia before data collection. Nevertheless, such residents without dementia would have also been identified by the nursing home staff and/or the GPs in the PACE study, as they were involved closely in resident care.[30,31]

Our study clearly showed that between 2010 and 2015, there is a substantially higher prevalence of nursing home residents with dementia with very minimal change in their clinical and socio-demographic characteristics. Over this relatively short period, almost an additional 1 in 4 residents die with dementia. Perhaps, this is because such increase in the prevalence of dementia also occurred in the home setting, as the 2016 estimates in Flanders suggest that there were 15,855 more people with dementia in 2015 than in 2010,[32] which is congruent with the current trends in dementia prevalence in other countries in Europe.[33] At the end of life, people with dementia also have complex care needs that could complicate primary care delivery and could thus become unmanageable at home.[34,35] Hence, more people with dementia living at home may have been transferred eventually to nursing homes.[13,14] Further, over the years, nursing home residents with dementia apparently remain to have almost similar clinical and demographic characteristics, which suggests that their complex and prolonged care needs at the end of life persist over the years.[34,35] We found that among residents in 2010 and 2015, about half had advanced dementia, more than 90% developed any clinical complication in the last month of life, and the majority stayed in nursing homes for about two years. While we found a somewhat lower percentage of residents who died with severe cognitive impairment in 2015 than in

2010, this finding suggests that these residents died with other diseases that do not result in cognitive impairment. Comorbidities, which often occur alongside old age and dementia, present additional challenges for healthcare service delivery to residents living and dying with dementia.[36]

In addition, our study showed that in the last week of life of residents with dementia between 2010 and 2015, there were some encouraging improvements in their use of medical/nursing procedures. However, their total comfort in the last week of life did not change. In particular, we found improvement in the use of pain assessment and correspondingly in the comfort level due to relief from pain and moaning which is a behavioural sign of pain;[37] and more residents received assistance with eating and drinking aiming to address intake problems that are common in advanced dementia.[35] However, the use of other medical/nursing procedures, psychosocial interventions, and spiritual care at the end-of-life seemed to lag behind. These findings underscore the persistent lack of attention given to the comprehensive care encompassing physical, psychosocial and spiritual support, which are paramount to improving residents' overall comfort at the end-of-life.[29]

Promoting comfort for nursing home residents with dementia is a key policy goal of care in many countries and a palliative care approach has been widely advocated to improve comfort in this population.[29,28-42] However, providing high-quality and comprehensive palliative care to and improving comfort in nursing home residents with dementia is a highly demanding and complex work for care professionals.[43] Our identified increase in the prevalence of nursing home residents with dementia and the minimal change in the complexity of their care needs at the end-of-life highlight the increasing complexity of the challenges faced by the nursing home sector. This evolution is likely to continue in the future, as the prevalence of dementia in Flanders has been projected to almost double by 2060.[32] Such evolution might also be comparable with evolution in other countries that implemented similar dementia and palliative care policies and initiatives and have similarly increasing dementia prevalence.[1,2,33] Further, we found that despite some encouraging improvements in the use of medical/nursing procedures, e.g. pain assessment, there remains a lack of improvement in their total comfort in the last week of life. In order to maintain the high quality of care in nursing homes and to improve comfort at the end-of-life of a growing number of residents with dementia,[32,44] there is an urgent need for continued and stronger public health investments and a more comprehensive palliative care approach in this sector.[29] The timely and consistent implementation of a comprehensive palliative care in dementia approach requires a strong national and regional policy commitment and the incorporation of this approach in the attitudes and skills of nursing home staff.[45-46] Because there is still no known effective palliative care program for nursing home residents with dementia,[47] future research should continue developing and evaluating palliative care programs that could improve comfort at the end-of-life in this population. Strategies on how to develop, implement and evaluate complex palliative care interventions in nursing homes and the factors that need to be addressed in doing so have been published.[48-50]

## 5. Conclusions

Our study suggests that between 2010 and 2015, there was a higher prevalence of residents with dementia in nursing homes in Flanders, Belgium who persistently have complex care needs at the end-of-life. Further, despite encouraging improvements in their use of some medical/nursing procedures, there remains a lack of improvement in their total comfort in the last week of life. These findings highlight the increasing complexity of

challenges faced by the nursing home sector, which underscores an urgent need to better support nursing homes in improving their capacities to provide timely, high-quality and comprehensive palliative care to a growing number of nursing home residents living and dying with dementia.

**Author Contributions:** RM, TS and LVDB made equal substantial contribution to conceptualising the design of the work. TS and NVDN collected the data. RM analysed the data and drafted and revised the manuscript critically for important intellectual content. All authors made substantial contribution to interpreting the data and revising the manuscript critically; have given the final approval of the manuscript to be submitted for publication; and have participated sufficiently in the work to take responsibility for appropriate portions of the content.

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**Informed Consent Statement:** The respondents participated voluntarily, returning a questionnaire was taken as consent to participation, and their anonymity was guaranteed by using unique anonymous identifier.

**Data Availability Statement:** The data that support the findings of this study are available from the corresponding author upon reasonable request.

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## References

1. Alzheimer Europe. Dementia in Europe Yearbook 2018: Comparison of national dementia strategies in Europe: Luxemburg, 2018.
2. Arias-casais N, Garralda E, Rhee JY, Lima L De, Pons JJ, Clark D, et al. EAPC Atlas of Palliative Care in Europe 2019: Belgium, 2019.
3. STATBEL: Belgium in figures. Structure of the Population: Belgium, 2020. Available from: <https://statbel.fgov.be/en/themes/population/structure-population> (accessed 20 Oct 2020).
4. Flemish Parliament. Flemish policy for older people 2010-2014 [Vlaams ouderenbeleidsplan 2010-2014]: Brussels, Belgium, 2011. 1–16.
5. Flemish Government. To a dementia-friendly Flanders: Dementiaplan Flanders 2010-2014c[Naar een dementievriendelijk Vlaanderen: Dementieplan Vlaanderen 2010-2014]: Belgium, 2010.
6. Flemish Parliament. Dementia - Evolution - Strategic policies [Dementie - Evolutie - Beleidsmaatregelen]: Brussels, Belgium, 2015. 1-4.
7. Flemish Government. Decree aiming to stimulate an inclusive Flemish policy for older people and policy participation of older people [Decreet houdende de stimulering van een inclusief Vlaams ouderenbeleid en de beleidsparticipatie van ouderen]:

Brussels, Belgium, 2012.

8. Flemish Government. Transition plan "Dementia expertise in basic care in the natural home setting" [Transitieplan 'Dementiekundige Basiszorg in het natuurlijk thuismilieu']: Brussels, Belgium, 2014.
9. Expertise Center Dementia Vlaanderen. Expertisecentrum Dementie Vlaanderen Annual reports: Antwerp, Belgium, 2020. Available from: <http://www.dementie.be/expertisecentrum-dementie-vlaanderen-vzw/organisatie/jaarverslag/> (accessed on 5 May 2020).
10. King Boudewijn Foundation. I will remain who I was: Ten years of working together for a dementia-friendly society [Ik blijf wie ik was: Tien jaar samen werken aan een dementievriendelijke samenleving]: Brussels, Belgium, 2018.
11. Flemish Parliament. Dementievriendelijke gemeente - Stand van zaken. Brussels, Belgium, 2018. Available from: <http://docs.vlaamsparlement.be/pfile?id=1416395> (Accessed 5 May 2020)
12. Flemish Parliament. Dementia - Training Psycho-education [Dementie - Opleiding psycho-educatie]: Brussels, Belgium, 2017. Available from: <http://docs.vlaamsparlement.be/pfile?id=1416395> (Accessed 5 June 2020)
13. Luppa, M.; Luck, T.; Brahler, E.; Konig, HH.; RiedelHeller, S.G. Prediction of institutionalisation in dementia: A systematic review. *Dement Geriatr Cogn Disord* **2008**, *26*, 65–78.
14. Eska, K.; Graessel, E.; Donath, C.; Schwarzkopf, L.; Lauterberg, J.; Holle, R. Predictors of institutionalization of dementia patients in mild and moderate stages: a 4-year prospective analysis. *Dement Geriatr Cogn Dis Extra* **2013**, *3*, 426–45.
15. Belgian Federal Government. Amendments of the 14 June 2002 law concerning palliative care Belgium, to expand the definition of palliative care [Wet tot wijziging van de wet 14 juni 2002 betreffende de palliatieve zorg, tot verruiming van de definitie van palliatieve zorg]: Belgium, 2016.
16. Flemish Parliament. Decree for Residential care [Decreet Woonzorgdecreet]: Brussels, Belgium, 2009. Available from: <https://codex.vlaanderen.be/Portals/Codex/documenten/1017896.html> (accessed 6 June 2020).
17. Federation for Palliative Care Flanders. Pallialine.be: Guideline for palliative care: Vilvoorde, Belgium, 2010. [cited 2020 Jul 22]. Available from: <http://www.pallialine.be/template.asp?f=welkom.htm> (accessed 6 June 2020).
18. Stabel, K.; Verstraete, A.; Mullie, S.; Vanden Berghe, P.; et al. Guideline for implementation of palliative care in nursing homes [Leidraad voor Implementatie Van Palliatieve Zorg in Woonzorgcentra]: Belgium, 2010.
19. Sevenants, A.; Spruytte, N.; Van Audenhove, C.; Flemish Indicator Project Nursing Homes: Guideline 1.6 [Vlaams Indicatorenproject Woonzorgcentra: Handleiding 1.6]: Belgium, 2015.
20. Vandervoort, A.; Van den Block, L.; van der Steen, J.T.; Volicer, L.; Vander Stichele, R.; Houttekier, D.; et al. Nursing home residents dying with dementia in Flanders, Belgium: a nationwide postmortem study on clinical characteristics and quality of dying. *J Am Med Dir Assoc* **2013**, *14*, 485–92.
21. Van den Block, L.; Smets, T.; van Dop, N.; Adang, E.; Andreasen, P.; Collingridge Moore, D; et al. Comparing Palliative Care in Care Homes Across Europe (PACE): Protocol of a Cross-sectional Study of Deceased Residents in 6 EU Countries. *J Am Med Dir Assoc* **2016**, *17*, 566.e1-566.e7.
22. Pivodic, L.; Smets, T.; Van den Noortgate, N.; Onwuteaka-Philipsen, B.D.; Engels, Y.; Szczerbińska, K.; et al. Quality of dying and quality of end-of-life care of nursing home residents in six countries: An epidemiological study. *Palliat Med* **2018**, *32*, 1584–95.
23. Morris, J.N.; Fries, B.E.; Mehr, D.R.; Hawes, C.; Phillips, C.; Mor V.; et al. MDS cognitive performance scale. *Journals Gerontol* **1994**, *49*, M174–82.
24. Reisberg, B. Ferris, S.H.; de Leon, M.J.; Crook, T. The Global Deterioration Scale for assessment of primary degenerative dementia. *Am J Psychiatry* **1982**, *139*, 1136–9.
25. Bellelli, G.; Frisoni, G.B.; Bianchetti, A.; Trabucchi, M. The Bedford Alzheimer Nursing Severity scale for the severely demented: Validation study. *Alzheimer Dis Assoc Disord* **1997**, *11*, 71–7.
26. Federation Palliative Care Flanders. Policy note: Palliative care in the nursing homes - a path to quality improvement

[Beleidsnota: Palliatieve zorg in de woonzorgcentra - een pad naar kwaliteitsverbetering]: Vilvoorde, Belgium, 2017.

27. Kiely D.K.; Volicer L.; Teno J.; Jones RN. The validity and reliability of scales for the evaluation of end-of-life care in advanced dementia. *Alzheimer Dis Assoc Disord* **2006**, *20*(3), 176–81.
28. Volicer, L; Hurley, A.C.; Blasi, Z.V. Scales for Evaluation of End-of-Life Care in Dementia. *Alzheimer Dis Assoc Disord* **2001**, *15*, 194–200.
29. van der Steen, J.T.; Radbruch, L.; Hertogh, C.M.P.M.; de Boer, M.E.; Hughes, J.C.; Larkin, P.; et al. White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care. *Palliat Med* **2014**, *28*, 197–209.
30. Parmar, J.; Dobbs, B.; McKay, R.; Kirwan, C.; Cooper, T.; Marin, A.; et al. Diagnosis and management of dementia in primary care: Exploratory study. *Can Fam Physician* **2014**, *60*, 457–65.
31. Elliott, A.F.; Hargas, A.L.; Marsiske, M. Nurses' Role in Identifying Mild Cognitive Impairment in Older Adults. *Geriatr Nurs (Minneap)* **2008**, *29*, 38–47.
32. Steyaert J, Expertise Centre Dementia Flanders. Prevalence: how many people die with dementia in Flanders [Prevalentie: hoeveel personen in Vlaanderen hebben dementie?] [Internet]. Handboek dementie. 2016. Available from: <http://www.dementie.be/wp-content/uploads/2016/05/2016-steyaert-prevalentie-dementie.pdf> (accessed 20 Oct 2020).
33. Alzheimer Europe. Dementia in Europe Yearbook 2019: Estimating the prevalence of dementia in Europe. Luxemburg, 2020.
34. Sampson, E.L. Candy, B. Davis, S. Gola, A.B.; Harrington, J.; King, M.; et al. Living and dying with advanced dementia: A prospective cohort study of symptoms, service use and care at the end of life. *Palliat Med* **2018**, *32*, 668–81.
35. Mitchell, S.L. Advanced dementia. *N Engl J Med* **2015**, *372*, 2533–40.
36. Bunn, F.; Burn, A.-M.; Goodman, C.; Robinson, L.; Rait, G.; Norton, S.; et al. Comorbidity and dementia: a mixed-method study on improving health care for people with dementia (CoDem). Vol. 4, *Health Services and Delivery Research*. 2016.
37. Kovach, C.; Griffie, J.; Muchka, S.; Noonan, P.; Weissman, D. Nurses' perceptions of pain assessment and treatment in the cognitively impaired elderly: it's not a guessing game. *Clin Nurse Spec J Adv Nurs Pract* **2000**, *14*, 215–20.
38. Alonzo, T. Hope for persons with Dementia: Why comfort matters. *Generations: Journal of American Society of Aging* **2017**, *4*, 81–5.
39. Parker, D.; Lewis, J.; Gourlay, K.; Dementia Australia's Dementia Advisory Committee. *Palliative Care and Dementia*. Vol. 43, Dementia Australia, 2017.
40. NHS: North West Coast Strategic Clinical Network. *Palliative care guidelines In dementia: 2nd Edition*. UK, 2018.
41. Alzheimer Europe. Dementia in Europe Yearbook 2017 Standards for residential care facilities in Europe. Luxemburg, 2020.
42. Prince, M.; Comas-Herrera, A.; Knapp, M.; Guerchet, M.; Karagiannidou, M. *World Alzheimer Report 2016 Improving healthcare for people living with dementia. Coverage, Quality and costs now and in the future*: London, UK, 2016, 1–140.
43. Midtbust, M.H.; Alnes, R.E.; Gjengedal, E.; Lykkeslet, E. Perceived barriers and facilitators in providing palliative care for people with severe dementia: The healthcare professionals' experiences. *BMC Health Serv Res* **2018**, *18*, 1–10.
44. Miranda, R.; Penders, Y.; Smets T.; Deliens, L.; Miccinesi, G.; Vega Alonso, T.; et al. Quality of primary palliative care for older people with mild and severe dementia: an international mortality follow-back study using quality indicators. *Age Ageing* **2018**, *47*, 824–33.
45. World Health Organization. *Global action plan on the public health response to dementia 2017 - 2025*. World Health Organization. Geneva, Switzerland, 2017, 1–52.
46. Smets, T.; Pivodic, L.; Piers, R.; Pasman, HRW.; Engels, Y.; Szczerbińska K.; et al. The palliative care knowledge of nursing home staff: The EU FP7 PACE cross-sectional survey in 322 nursing homes in six European countries. *Palliat Med* **2018**, *32*, 1487–97.
47. Van den Block, L.; Honinx, E.; Pivodic, L.; Miranda, R.; Onwuteaka-Philipsen, B.D.; van Hout, H.; et al. Evaluation of a Palliative Care Program for Nursing Homes in 7 Countries The PACE Cluster-Randomized Clinical Trial. *JAMA Intern Med* **2020**, *180*, 233–42.

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48. Collingridge Moore, D.; Payne, S.A.; Van den Block, L.; Ling, J.; Froggatt, K.; Gatsolaeva, Y. et al. Strategies for the implementation of palliative care education and organizational interventions in long-term care facilities: A scoping review. *Palliat Med* **2020**, *34*, 558–70.
49. Froggatt, K.A.; Collingridge Moore D.; Van den Block, L.; Ling, J.; Payne, S.A.; PACE consortium collaborative authors on behalf of the European Association for Palliative Care. Palliative Care Implementation in Long-Term Care Facilities : European Association for Palliative Care White Paper. *J Am Med Dir Assoc* **2020**, *21*, 1051–7.
50. Collingridge Moore, D.; Payne S.A.; Van Den Block, L.; Ten Koppel, M.; Szczerbińska K.; Froggatt, K.; Research, recruitment and observational data collection in care homes: Lessons from the PACE study. *BMC Res Notes* **2019**, *12*, 1–6.