

## Appropriateness of End-of-Life Care in People Dying With Dementia

De Schreye, Robrecht; Smets, Tinne; Deliens, Luc; Annemans, Lieven; Gielen, Birgit; Cohen, Joachim

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## **Abstract**

### **1 Objectives**

2 Dementia is a progressive incurable life-limiting illness. Previous  
3 research suggests end-of-life care for people with dementia should  
4 have a symptomatic focus with an effort to avoid burdensome  
5 interventions that would not improve quality of life.

6 This study aims to assess the appropriateness of end-of-life care in  
7 people who died with dementia in Belgium and to establish relative  
8 performance standards, by measuring validated population-level  
9 quality indicators (QIs).

### **10 Design**

11 We conducted a retrospective observational study.

### **12 Setting and participants**

13 We included all persons deceased with dementia in 2015 in Belgium.  
14 Data from eight administratively collected population-level databases  
15 was linked.

### **16 Measures**

17 We used a validated set of 28 quality indicators for end-of-life  
18 dementia care. We compared quality indicator scores across 14 health  
19 care regions to establish relative benchmarks.

### **20 Results**

21 In Belgium in 2015, 10,629 people died with dementia. For indicators  
22 of appropriate end-of-life care, people who died with dementia had  
23 on average 1.83 contacts with their family physician in the last week

24 before death, while 68.4 percent died at home or in their nursing  
25 home of residence.

26 For indicators of inappropriate end-of-life care, 32.4 percent were  
27 admitted to hospital and 36.3 percent underwent diagnostic testing  
28 in the last 30 days before death, while 25.1 percent died in the  
29 hospital. In the last 30 days, ED admission varied between 19 and 31  
30 percent, dispensing of gastric protectors between 18 and 42 percent,  
31 and anti-hypertensives between 40 and 53 percent between health care  
32 regions, with at least 25% of health regions below 46 percent.

### 33 **Conclusions and implications**

34 Our study found indications of appropriate as well as inappropriate  
35 end-of-life care in people with dementia, including high rates of  
36 family physician contact, as well as high percentages of diagnostic  
37 testing and ED and hospital admissions. We also found high risk-  
38 adjusted variation for multiple QIs, indicating opportunity for  
39 quality improvement in end-of-life dementia care.

40

41

## 42 Background

43 Dementia is a progressive incurable life-limiting illness and its  
44 prevalence is increasing worldwide. Dementia contributes strongly to  
45 functional disability, care dependence and institutionalization in  
46 the older population.<sup>1,2</sup> People with dementia experience progressive  
47 cognitive and physical impairment and often suffer from burdensome  
48 symptoms and clinical complications at the end of life.<sup>3-5</sup> In contrast  
49 with people suffering from cancer or organ failure, their disease  
50 trajectory is characterized by a gradual functional decline.<sup>6-8</sup>

51 Because of this irreversible gradual decline, experts advocate the  
52 main care goals for people with advanced dementia include providing  
53 a comfortable, painless, dignified end of life, while avoiding  
54 unnecessary treatment, medication and care transitions.<sup>6,9,10</sup> However,  
55 experts are concerned that these goals are often not met and  
56 inappropriate end-of-life care for people with dementia is  
57 occurring.<sup>6,11,12</sup> Appropriate end-of-life care, regardless of the  
58 disease, can be defined as receiving care of which the expected health  
59 benefit (e.g. increased life expectancy or symptom relief) exceeds  
60 possible negative outcomes (e.g. mortality, loss of quality of  
61 life)<sup>13,14</sup>.

62

63 Using a RAND/UCLA Appropriateness method, we developed a set of  
64 quality indicators that measure aspects of care that may indicate  
65 appropriate or inappropriate care at the end of life in people who

66 died with dementia.<sup>10</sup> The set includes indicators on aggressiveness of  
67 care, pain and symptom management, specialized palliative care  
68 delivery, place of care and death and continuity of care. The  
69 indicators were developed specifically to be used at a population  
70 level, using administrative health data. The use of the indicators,  
71 in a benchmarking of different health care regions, also allows to  
72 set relative performance standards as attainable targets for quality  
73 improvement.<sup>15</sup> Previous population-level health care research found  
74 substantial variation in health care provision across health care  
75 regions in Belgium.<sup>16,17</sup> If variation in appropriateness of care is  
76 found between regions, although government policy and funding across  
77 all regions are equal (e.g. reimbursement of care), this means  
78 variation in practice indicates opportunities for improvement in  
79 regions where appropriate care is more prevalent. This is a first  
80 step towards improvement of the quality of end-of-life care and it  
81 is novel in dementia research.

82 The aims of our study are threefold:

83 1. To assess the quality of end-of-life care in all people who died  
84 with dementia in Belgium using previously validated quality  
85 indicators of potentially appropriate or inappropriate end-of-life  
86 care.

87 2. To compare the quality indicator scores of end-of-life care in  
88 people who died with dementia between all health care regions within  
89 the country.

90 3. To establish relative performance standards based on this  
91 comparison.

92

93

## 94    **Method**

### 95    *Study design and data sources*

96    We conducted a retrospective observational study of all deceased with  
97    dementia in 2015 in Belgium. Data from eight administratively  
98    collected population-level databases was linked into one database for  
99    analysis<sup>18</sup> (supplementary appendix S1 provides a detailed description  
100    of the databases):

101    (1) Socio-demographic database of all individuals with healthcare  
102    insurance (legally mandatory in Belgium);

103    (2) Health care database containing all reimbursed health care use  
104    data of home, nursing home and hospital care, except medication  
105    dispensed in public pharmacies;

106    (3) Pharmaceutical database containing all reimbursed medication data  
107    dispensed in public pharmacies;

108    (4) Cancer Registry database with diagnostic information on all  
109    incidences of cancer including type of cancer and date of diagnosis;

110    (5) Death certificate database containing all reported causes of  
111    death;

112    (6) Population registry database including household composition;

113    (7) Census database, including housing characteristics and  
114    educational level;

115    (8) Fiscal database, including net taxable income;

116 After acquiring approval from all relevant data protection agencies,  
117 all databases were linked in a secure and ethically responsible  
118 manner, guaranteeing anonymity of the deceased. The database linking  
119 procedure is described in detail in a previous publication.<sup>18</sup>

120

## 121 *Population*

122 All people who died with dementia in 2015 were identified based on  
123 the underlying, intermediate and associated causes of death reported  
124 on the death certificate, coded in ICD-10 codes (F00 or G30).

125

## 126 *Data*

127 In the Belgian health care system, health care costs are reimbursed  
128 directly to the patient by health insurers and every reimbursement  
129 is registered. A central agency collects the data from all health  
130 insurance registries in a central health care database and pharmacy  
131 database, which were part of the linking procedure mentioned in the  
132 methods section. This provides detailed information on every care  
133 action that was reimbursed. We used all available data on health care  
134 use including medication use, treatment, dates of treatment and  
135 prescription and admission to hospitals and nursing homes. Multiple  
136 socio-economic, demographic and clinical variables were selected,  
137 including age, gender, dependence on care, highest attained level of



138 education, household composition, degree of urbanization of the  
139 municipality of residence and net taxable income.

140

#### 141 *Quality indicators*

142 We used a validated set of 28 quality indicators for end-of-life  
143 dementia care. It was developed and validated using a RAND/UCLA  
144 Appropriateness method.<sup>10,19</sup> The expert panel consisted of neurologists,  
145 pharmacologists, nursing home coordinating and advisory physicians,  
146 geriatrists and palliative care specialists. The quality indicators  
147 measure the prevalence of specific healthcare interventions in a  
148 specified period before death. We measured all indicators 7, 14, 30,  
149 90, 180, 360 and 720 days prior to death, except the periods for  
150 which the specific indicators were not validated by the expert panel  
151 (as indicated in table 1). One indicator on tube feeding or  
152 intravenous feeding could not be measured, as they are reimbursed as  
153 a package in the hospital context, not as individual interventions.

154

#### 155 *Risk factors for comparison across health care regions and relative* 156 *benchmarks*

157 For the comparison of QIs across health care regions, we performed  
158 risk adjustment procedures. The northern part of Belgium has 14 major  
159 health care regions, based on natural patient flow towards major  
160 hospitals in each region.<sup>20</sup> These regions cover the administrative

161 regions of Flanders and Brussels; no equivalent exists in the Walloon  
162 region. We therefore limited this analysis to Flanders and Brussels.  
163 To obtain a fair comparison across health care regions, we performed  
164 risk adjustment procedures. We started from a comprehensive list of  
165 possible risk factors<sup>21</sup> and made a selection based on availability of  
166 data in the current dataset. The following risk factors were  
167 identified as relevant and measurable with the current dataset: age,  
168 gender, living situation (e.g. alone, with children, in a nursing  
169 home), being entitled to a higher degree of reimbursement due to  
170 lower degree of self-reliance, being officially recognized by the  
171 physician as having heavy care needs, frequent (more than 5 in the  
172 same year) or extended (at least 120 days in one year) hospital stays,  
173 highest level of education, household composition, degree of  
174 urbanization of the municipality of residence and net taxable income.

175

#### 176 *Statistical analyses*

177 The characteristics of the decedents with dementia and the quality  
178 indicators were calculated using descriptive statistics.

179 Risk adjusted comparison and the establishment of relative benchmarks  
180 consisted of four steps:

181 1) We evaluated the effects of the potential risk factors on  
182 individuals' outcomes for each of the quality indicators (coded  
183 binary as present [1] or absent [0]) using logistic regression. We  
184 used the period of 30 days before death for all indicators, or closer

185 to death if the indicator was validated only for a shorter period  
186 before death.

187 2) We used stepwise model building, with a significance level of 0.3  
188 for entry and significance level of 0.05 to stay in the model. Based  
189 on the logistic regression, predicted scores (between 0 and 1) were  
190 calculated for each individual. For example: age and being entitled  
191 to a higher degree of reimbursement due to lower degree of self-  
192 reliance were associated with higher ICU admission, while living in  
193 a nursing home was associated with lower ICU admission. No other  
194 socio-demographic variables were withheld by the stepwise model-  
195 building process for ICU admission.

196 3) For each health care region, an average risk adjusted score was  
197 calculated by dividing the average predicted score by the average  
198 observed score for that health care region, multiplied by the average  
199 observed score across all regions. In the example of ICU admission,  
200 this score was calculated using the age, lower degree of self-reliance  
201 and living in a nursing home for all people who died of dementia  
202 living in this each region.

203 4) To establish relative benchmarks, quartiles across health care  
204 regions were calculated for each quality indicator. For indicators  
205 of appropriate care, the relative benchmark was established at the  
206 third quartile (or above), while for indicators of inappropriate  
207 care, the relative benchmark was established at the first quartile  
208 (or below).

209 All analyses were conducted with SAS Enterprise Guide, version 7.1.

210 *Ethics*

211 The study was approved by a university hospital committee for medical  
212 ethics (B.U.N. 143201627075). The administrative data linking process  
213 was approved by the national Belgian Data Protection Authority  
214 (project SA1/STAT/MA-2015-026-020-MAV) and by the Statistical  
215 Monitoring Committee (project STAT-MA-2015-026).

216

## 217 **Results**

### 218 *Study Population Characteristics*

219 The study population consisted of 10,629 people who died with dementia  
220 in Belgium in 2015 (10.6 percent of all deceased), of whom 65.8  
221 percent were women. The mean age at death was 85 (data not shown).  
222 46.5 percent lived in a collective household (most likely a nursing  
223 home). 7.8 percent completed higher education and 8.6 percent did not  
224 complete primary education. 59.7 percent lived in a highly or very  
225 highly urbanized region. (Table 2)

226

### 227 *Quality Indicators of Appropriate End-Of-Life Care*

228 Of all people who died with dementia in Belgium in 2015, 9.8 percent  
229 received specialist palliative care, and 68.4 percent died at home  
230 or in the nursing home where they lived. Of all people living in a  
231 nursing home at least 180 days before death, 79.2 percent died in the  
232 nursing home. (data not shown) 60.2 percent had an increase in family  
233 physician contacts during the last week of life compared with the  
234 period before, with an average of 1.83 reimbursed contacts per week  
235 during the last week of life. (Table 3)

236

### 237 *Quality Indicators of Inappropriate End-Of-Life Care*

238 Of all people who died with dementia, 25.6 percent were admitted to  
239 an emergency department, 32.4 to hospital and 2.2 to ICU during the  
240 last 30 days of life. 25.1 percent of people died in the hospital.

241 In the last two weeks prior to death, 25.8 percent of people who died  
242 with dementia was submitted to diagnostic testing (medical imaging,  
243 ECG or pulmonary function testing). 0.8 percent received surgery  
244 during the last 30 days.

245 Of those who died with dementia and had a cancer diagnosis, 1.7  
246 percent received chemotherapy during the last 30 days prior to death.

247 Regarding drug dispensing in the last 30 days prior to death, 43.8  
248 percent received anti-hypertensives, 38.5 percent received NOACs or  
249 vitamin K antagonists, 26.5 percent received gastric protectors and  
250 6.5 percent received statins.

251 Of those who received specialist palliative care 38.3 percent  
252 received it only in the last week, which corresponds to 3.7 percent  
253 of the total population who died with dementia. (Table 4)

254

255 *Comparison of quality indicator scores of end-of-life dementia care*  
256 *between health care regions*

257 Variation of scores between different health care regions in Flanders  
258 and Brussels (N = 7,581) is found for the indicators of appropriate  
259 end-of-life-care (Figure 1): dying at home or in a nursing home of  
260 residence varies between 52 and 62 percent, with the best scoring

261 quartile scoring above 59 percent. Having an increase in contacts  
262 with the family physician in the last 30 days compared to the period  
263 before varies between 72 and 86 percent, with the best scoring  
264 quartile above 83 percent. The use of specialist palliative care  
265 varies between 5 and 11 percent between regions, with the best scoring  
266 quartile scoring above 9 percent.

267 The use of diagnostic testing in the last 30 days varies from 21 to  
268 35 percent between regions, with the best scoring quartile scoring  
269 below 26 percent (Figure 2). ED admission in that period varies  
270 between 10 and 25 percent, with the best scoring quartile scoring  
271 below 14 percent. Dispensation of gastric protectors in the last 30  
272 days varies between 21 and 30 percent, with the best scoring quartile  
273 below 22 percent, while anti-hypertensives in the last 30 days varies  
274 between 37 and 49 percent, with the best scoring quartile below 41  
275 percent. The quality indicator measuring port-a-cath installment was  
276 not included in this comparison, since variation was low.

277

278 Based on these results, we suggest a relative benchmark for each  
279 indicator, set at the best scoring quartile. (Table 5)

280

## 281 **Discussion**

### 282 *Summary of main findings*

283 Using a validated set of quality indicators to describe the quality  
284 of end-of-life care in people who died with dementia, we found  
285 remarkable percentages for several indicators of appropriate care.  
286 The majority died at home or in a nursing home of residence (68.4  
287 percent), with large variation across health care regions.  
288 Specialized palliative care was not used very often. We also found  
289 large percentages for several indicators of inappropriate care,  
290 including the percentage of people with dementia dying in the hospital  
291 (25.0 percent), which is comparable to previous research<sup>12</sup>. Many  
292 people with dementia receive gastric protectors (26.5 percent),  
293 antihypertensives (43.8 percent), NOACs or vitamin K antagonists  
294 (38.5 percent) in the last month before death, with large variation  
295 across health care regions.

296

### 297 *Strengths and limitations*

298 Our study provides an insightful overview of end-of-life care  
299 provision for people who died with dementia. The use of routinely  
300 collected administrative data is a main strength of this study. In  
301 contrast to studies using sample data, the use of administrative data  
302 precludes sampling, nonresponse and recall bias.<sup>22,23</sup> Studying end-of  
303 life care in a vulnerable population like people with dementia is  
304 otherwise ethically and methodologically challenging. Additionally,



305 administrative data are relatively inexpensive,<sup>24</sup> as they are  
306 routinely collected by health insurance companies (for example, in  
307 the United States, Japan and Belgium) or by governments (for example,  
308 in the United Kingdom).

309 A second main strength of this study is the linking and use of socio-  
310 demographic and death certificate databases, which provide background  
311 variables to make a fair comparison between health care regions,  
312 taking into account socio-demographic and economic differences  
313 between regions.

314 The third main strength of this study is that the results are directly  
315 comparable to those in other countries, such as the US, Canada or the  
316 UK. This goes for the quality indicator results, as well as the  
317 relative benchmarks. The methodology we use to measure quality  
318 indicators and to establish relative benchmarks is novel and can also  
319 be replicated in other countries.

320 A limitation of this study is that the linked administrative data do  
321 not include diagnostic information. We therefore must rely on death  
322 certificate data to select the dementia population. Literature  
323 suggests death certificate data tend to underestimate the prevalence  
324 of dementia.<sup>25-27</sup> To identify comorbidities that might influence  
325 treatment, we used death certificate data as a proxy, where  
326 diagnostics data would be more accurate.

327 Furthermore, the linked administrative databases do not contain data  
328 on non-reimbursed care. As such, palliative care included in regular

329 nursing home care and generalist palliative care by the family  
330 physician or other carers are not measured in quality indicators  
331 measuring specialist palliative care. They do not contain data on  
332 non-reimbursed medication, except for laxatives, calcium combinations  
333 and several analgesics that are registered, although not reimbursed.  
334 This affects the results for the gastric protectors and calcium with  
335 vitamin D quality indicators. In practice, they are dispensed to a  
336 higher percentage of people with dementia than calculated in these  
337 indicators.

338 Data on non-reimbursed care and diagnostic information would increase  
339 the robustness of the risk adjustment method and reduce the  
340 possibility that some of the variation between regions is due to  
341 unmeasured confounders at the individual level.

342

### 343 *Interpretation*

344 Several indicators of inappropriate end-of-life care are highly  
345 prevalent, especially hospital death, diagnostic testing and ED  
346 admission. Similar results were found in previous research in the US  
347 and the UK.<sup>28,29</sup> This suggests a high number of people who died with  
348 dementia underwent an aggressive curative trajectory with one or more  
349 care transitions. This occurs in people who lived in a nursing home  
350 as well as people who lived at home. We also found large variations  
351 across health care regions on these indicators, even when taking into  
352 account a number of relevant confounding variables. This indicates

353 there are opportunities for improvement, at least in several regions.  
354 Especially for these indicators, ambitious and realistic standards  
355 should be established to decrease the number of hospital deaths, ED  
356 admissions and diagnostic tests, and thus increase the quality of  
357 end-of-life care for people dying with dementia.

358 Specialized palliative care is remarkably rare in people who died  
359 with dementia, taking into account the progressive and terminal  
360 nature of the disease, especially compared to people dying with  
361 cancer<sup>30</sup>. A large percentage of those who receive it, do so only in  
362 the last week before death (47.7 percent). There are three plausible  
363 causes for this: first, palliative care included in regular nursing  
364 home care is not measured in this indicator, which might occur often  
365 in people who died with dementia.<sup>4,31</sup> Secondly, during the dementia  
366 disease trajectory, prognosis of functional decline more than several  
367 months ahead is often difficult.<sup>3,9</sup> This makes the decision to initiate  
368 palliative care especially difficult.<sup>7,10</sup>

369 Thirdly, health care providers are not always aware that palliative  
370 care is appropriate for people suffering with dementia, or that  
371 dementia is a life-limiting condition.<sup>32</sup>

372 We found high percentages of people using antihypertensives, gastric  
373 protectors and NOACs or vitamin K antagonists. These medications  
374 mainly have a prophylactic rather than an aggressive curative  
375 function. They can and should be discontinued when patients near the  
376 end of life, to avoid adverse effects and costs when no benefits are  
377 present.<sup>33,34</sup> Our findings are corroborated by recent research on

378 polypharmacy.<sup>35,36</sup> The indicators on antihypertensives, gastric  
379 protectors and NOACs or vitamin K antagonists mark an area where we  
380 have the opportunity and necessity to enhance the quality of end-of-  
381 life care for people with Dementia.

382

### 383 *Towards quality improvement*

384 We indicated three main opportunities for quality improvement:  
385 reducing care transitions and aggressive care (e.g. diagnostic  
386 testing, ED admissions, hospital death), earlier initiation of  
387 palliative care and discontinuation of prophylactic medication (e.g.  
388 antihypertensives, gastric protectors and NOACs or vitamin K  
389 antagonists) near the end of life. As we controlled for the most  
390 impactful population differences across regions, such as differences  
391 in degree of urbanization, income, age, or education level, variation  
392 across regions is likely to be determined by real differences in  
393 health care practice across regions. The suggested standards for  
394 these indicators, based on the fair comparison between regions, are  
395 a starting point for quality improvement.<sup>15</sup> These standards are both  
396 ambitious and attainable, as currently 25% of regions achieve them.

397 To improve practice, policy makers can use the suggested benchmarks  
398 to further analyze the reasons for the inconsistencies between  
399 regions, and develop and test interventions that can improve practice  
400 within a region.<sup>37,38</sup> For instance, the implementation of advance care  
401 planning can support the decision making process when treating people  
402 with dementia.<sup>39</sup> This might in turn lead to earlier initiation of

403 palliative care, fewer care transitions and discontinuation of  
404 ineffective medication near the end of life.

405

## 406 **Conclusions and implications**

407 The evidence in this study suggests the occurrence of potentially  
408 inappropriate end-of-life care in people who died with dementia in  
409 Belgium, especially diagnostic testing, hospital and ED admissions,  
410 lack of discontinuation of potentially inappropriate medication and  
411 late initiation of specialized palliative care. We found substantial  
412 risk-adjusted variation between regions for multiple QIs, suggesting  
413 opportunities for quality improvement in dementia end-of-life care.  
414 A first step towards quality improvement could be using evidence-  
415 based relative standards, as developed in this study.

416

## 417 **Conflict of interest**

418 The authors have no conflicts of interest to declare. All individuals  
419 who merit authorship are included as authors.

420

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## Figure Legend

Table 1: Quality indicators with detailed description

Table 2: Characteristics of all deaths from or with dementia, Belgium, 2015.

Table 3: Quality indicators indicating appropriate end-of-life care, within the total population dying with dementia (N=10,629), Belgium, 2015

Table 4: Quality indicators indicating inappropriate end-of-life care, within the total population dying with dementia (N=10,629), Belgium, 2015.

Figure 1: Figure 1: Risk adjusted comparison between all health care regions in Flanders and Brussels on indicators indicating appropriate end-of-life care, within the population who died with dementia (N=7,581), 2015

Figure 2: Risk adjusted comparison between all health care regions in Flanders and Brussels on indicators indicating inappropriate end-of-life care, within the population who died with dementia (N=7,581), 2015

Table 5: Suggestions of relative benchmarks for indicators, set at the best scoring quartile of regional comparison in Flanders, as a goal to be pursued on a national level in Belgium. (all measured at 30 days before death where time is relevant)

Supplementary table S1: Overview of population-level databases identified as relevant for end-of-life care research