



## 12 CARE AT THE END OF LIFE

When the end of life is near and recovery is no longer possible, the care provided needs to change its purpose and instead focus on improving quality of life for the patients and their families, by preventing and relieving pain, whether physical or psychological, social or spiritual. This is what is called palliative care. This is a holistic approach which takes into consideration the different aspects of end-of-life problems, in a necessarily multidisciplinary way. Palliative care is for any person who is in a life-threatening condition (and not only for terminal cancer patients, as is sometimes believed), as well as for their families and close relatives.

Belgium has set up a high-performance palliative care system. **Palliative networks** have been installed in all provinces to organise training courses, coordinate and evaluate the actions of the different services, and ultimately promote the spread of a palliative care 'culture'.

For people who wish to end their days in their home, there are teams who are specialised in **palliative home care** and who also provide support to the patient's close relatives. In some regions, **daytime palliative care facilities** have also been set up in order to provide relief to patients and their families.

In hospitals, two types of palliative care facilities have been set up: **small palliative care units** (offering a total of approximately 400 beds for the whole country), and **mobile teams** who provide specific support to end-of-life patients who are hospitalised in other units (than the palliative care unit). A similar palliative function has been created in homes for older people.<sup>137</sup>

It has also been ensured that palliative care is financially accessible to all. When at home, therefore, palliative care patients do not need to pay any personal contribution for procedures performed by general practitioners, nor for certain procedures performed by nurses and physical therapists. There

is also a palliative flat fee which covers additional costs generated by this care.

In addition to palliative structures, Belgium has a legal regulation for euthanasia in adults and children.<sup>138</sup>

Since November 2022, there is a new RIZIV-INAMI billing code for Advance Care Planning (ACP) for GPs, which is fully reimbursed to the patient. ACP is one of the ways to enhance quality of palliative care. With ACP, the GP analyses together with the patient his or her expectations and wishes regarding future, either curative or palliative, care. This billing code was too recently introduced to analyse its introduction and evolution over time in this report, but it certainly forms an interesting indicator to evaluate in a future edition of the performance report.

In what follows, we focus on end-of-life care for cancer patients. In the discussion and conclusion of this chapter, we will make reference to a broader Belgian study analysing appropriateness and inappropriateness of end-of-life care for two other patient groups besides cancer: COPD and dementia.

### Access to and timing of palliative care received by cancer patients

The first two indicators in this chapter present data on palliative care received by cancer patients. In 2020, 56.8% of terminal cancer patients received palliative care (EOL-1), either at home or in hospital.<sup>w</sup> This percentage slightly increased over time and was higher in Flanders than in the other regions. This percentage is probably an underestimation of the reality, as patients may receive palliative care in the hospital without specific billing.

Yet, 18.6% of terminal cancer patients died within one week after the start of palliative care (EOL-2). Since 2013, this indicator stayed below 19% but there was no large improvement. The result remains a warning signal for

<sup>w</sup> Palliative care as identified in billing data: this includes patients receiving a lump sum for palliative care at the usual place of residence, patients with visits

of the general practitioner or nurse within a palliative setting, patients hospitalised in palliative units or hospitalised patients with visits of multidisciplinary palliative care teams.



healthcare providers and patients to be aware of the importance of a well-timed initiation of palliative care.

### **Aggressiveness of care at the end of life in cancer patients**

In addition to appropriate timing of palliative care, aggressiveness of care (e.g. inappropriate treatments in the final phase of life) can also be an important source of information for both healthcare providers and policymakers.<sup>139</sup> About 10.6% of terminal cancer patients still received chemotherapy in the last 14 days of their life (data from 2020) (EOL-3), with slightly higher rates in Wallonia. The data, however, make no distinction between curative and palliative chemotherapy, nor with unexpected deaths in cancer patients, which hampers the interpretation of these results. Since 2008, there was no substantial change in this indicator.

### **People-centred care**

In spite of the current organisation of palliative services supporting the patient and his or her relatives to help the patient stay at home, 56.7% of cancer patients died in a hospital, 28.6% died at home and 3.1% in home for older people (thus 31.7% died in their usual place of residence, EOL-4) (data from 2020). The proportion of patients who died in a hospital was higher in Brussels. Over the period 2008-2019, there was a small decrease in patients who died in hospital (from 65.3% in 2008 to 63.1% in 2019). In 2020, likely due to the COVID-19 crisis, there was a considerable drop in patients who died in hospital (56.7% in 2020) (see also section 8.4 on the impact of the COVID-19 pandemic).

In general, patients should die as much as possible in their preferred place of death. However, it is unknown what proportion of patients prefers to die at home, in residential care or elsewhere, so the indicator has to be interpreted with caution. Healthcare professionals are encouraged to record patients' preferred place of death. These data could then be used to monitor the percentage of deaths in preferred place, which would be a more accurate indicator of people-centred care.

### **Conclusion and discussion**

The four indicators focused on accessibility, timeliness, aggressiveness of therapy and people-centredness in cancer patients, showed a stable or slightly positive evolution since the previous performance report. However, they only give a partial image of the current practice of end-of-life care in Belgium, as it only concerns cancer patients. A recent Belgian study<sup>140</sup> analysed the appropriateness of end-of-life care in a broader group of patients, including besides cancer, COPD and dementia. For each of these three patient groups, a set of indicators for appropriateness of end-of-life care were developed and validated, comprising 26 indicators for people dying from cancer, 28 indicators for people dying from COPD, and 28 indicators for people dying with dementia. With regard to *appropriateness* of end-of-life care, the following indicators were analysed, most of which are common across the three patient groups:

- Number of contacts with GP
- Specialist palliative care
- Official palliative care status
- Opioids/opioids and neuropathic medication
- Death at home / Death at home or in home for older people
- Multidisciplinary oncology consult (for cancer)

With regard to *inappropriateness* of end-of-life care, the indicators were specific for each patient group:

- For cancer: Chemotherapy / Feeding tube or intravenous feeding
- For COPD: Continuous endotracheal intubation / Reanimation after Intubation / Coronary or abdominal surgery / Endotracheal intubation or tracheotomy / Repeated endotracheal Intubation / Inhalation therapy / Late initiation of physiotherapy
- For dementia: serotonin reuptake inhibitors / antihypertensives / NOAC's or vitamin K antagonists / prophylactic gout medication / statins / gastric protectors / chemotherapy / calcium vitamin D



- For all three patient groups:
  - Late initiation of palliative care
  - Hospital admissions / ICU / ED
  - Start taking antidepressant
  - Blood transfusion
  - Diagnostic testing: all / ECG or pulmonary function testing / medical imaging
  - Surgery
  - Hospital death (for COPD and dementia)

Overall, the authors of this Belgian study concluded that over time (period 2010-2016) there was an improvement in several indicators of appropriateness (such as use of specialized palliative care and GPs), but little reduction in indicators of inappropriateness (such as use of emergency department and ICU). This suggests that palliative care was often given on top of aggressive treatment and did not actually replace it. Systematic monitoring of quality indicator scores could help define goals for future improvement of the quality of end-of-life care.<sup>140</sup>



Table 26 – Indicators on end-of-life care (cancer)

| (ID) Indicator                                   | Score  | Belgium | Year | Flanders | Wallonia | Brussels   | Source     | EU-14         | EU-27 |   |
|--|--|---------|------|----------|----------|------------|------------|---------------|-------|---|
| <b>Access to palliative care</b>                 |  |         |      |          |          |            |            |               |       |   |
| <b>EOL-1</b>                                     | Cancer patients who received palliative care at the end of their life (% of cancer patients with poor prognosis who died) <sup>a</sup>   |         | 57%  | 2020     | 62%      | <b>50%</b> | <b>49%</b> | BCR – IMA-AIM | -     | - |
| <b>Timeliness of palliative care</b>             |  |         |      |          |          |            |            |               |       |   |
| <b>EOL-2</b>                                     | Cancer patients who started receiving palliative care and died within one week after start of palliative care (% of cancer patients with poor prognosis who received palliative care and died) |         | 19%  | 2020     | 17%      | <b>22%</b> | <b>22%</b> | BCR – IMA-AIM | -     | - |
| <b>Aggressiveness of care at the end of life</b> |  |         |      |          |          |            |            |               |       |   |
| <b>EOL-3</b>                                     | Cancer patients who received chemotherapy in the last 14 days of life (% of cancer patients with poor prognosis who died)  |         | 11%  | 2020     | 9%       | <b>12%</b> | <b>11%</b> | BCR – IMA-AIM | -     | - |
| <b>People-centred care</b>                       |  |         |      |          |          |            |            |               |       |   |
| <b>EOL-4</b>                                     | Death at usual place of residence (home or in residential care) (% of cancer patients with poor prognosis who died)  | C       | 32%  | 2020     | 31%      | 35%        | 23%        | BCR – IMA-AIM | -     | - |

Good (●), average (●) or poor (●) results, globally stable (ST), improving (+) or trend not evaluated (empty).  
 For contextual indicators (no evaluation): upwards trend (↗), stable trend (→), downwards trend (↘), no trend (C).

<sup>a</sup> Palliative care as identified in billing data: this includes patients receiving a lump sum for palliative care at their usual place of residence, patients with visits of the general practitioner or nurse within a palliative setting, patients hospitalized in palliative units or hospitalized patients with visits of multidisciplinary palliative care teams