



13. CARE AT THE END OF LIFE

13.1. Patients with terminal cancer who received palliative care (EOL-1)

13.1.1. Documentation sheet

Description	Terminal cancer patients who received palliative care at the end of their life
Calculation	Numerator: Number of patients who received palliative care (in usual place of residence or in hospital) (regardless of time period) Denominator: Number of patients diagnosed with a cancer with poor prognosis and that died within the studied time period
Rationale	<p>The 2002 WHO definition states that “palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”.</p> <p>Belgium has developed many structures and services for palliative patients. Palliative networks were created in 1997, to develop palliative care culture, to organize trainings for caregivers, to coordinate actions between organisations and services, to evaluate the palliative services.</p> <p>In home settings, palliative home care teams support caregivers and facilitate the care for the palliative patient who wishes to stay at home by additional measures. Firstly, a “palliative lump sum” (so called “forfait”) covers the additional costs created by palliative care during two months. Furthermore, the palliative patient at home does not have to pay any personal contribution when treated by nurses, physiotherapists and general practitioners. Finally, through palliative day centres the supporting families can be offered some respite.</p> <p>Two types of palliative care structures were set up in the hospitals. First, approximately 400 specialised (SP)-palliative beds are clustered in small Palliative Care Units (PCU). Secondly, the palliative function has been developed in all hospitals in order to provide specific tailored care for palliative patients not staying in a PCU. A similar palliative function has been created in nursing homes.¹</p>
Data source	Belgian Cancer Registry (BCR), linked with IMA data
Technical definitions	<p>It is currently not possible to identify all palliative patients in administrative databases or in registries. Therefore, the indicator has been restricted to patients diagnosed with cancer having a poor prognosis and deceased during the study period.</p> <p><u>Inclusion Criteria</u></p> <p>Incidence years: 2006-2015</p> <p>Tumour selection based on the Pallcare project ² : combination of topography and morphology according to Eurocare-4 ^{3 4}, and Eurocare-5 ⁵</p> <ul style="list-style-type: none"> • Chronic tumours (5-yr RS <50%) <ul style="list-style-type: none"> ○ Head and neck ○ Nasal cavities and sinuses ○ Small intestine ○ Multiple myeloma ○ Ovary and uterine adnexa ○ Chronic myeloid leukaemia ○ Acute lymphatic leukaemia



- Acute tumours (1-yr RS <50%)
 - Lung, bronchus and trachea
 - Pleura
 - Oesophagus
 - Stomach
 - Gallbladder and biliary tract
 - Liver, primary
 - Pancreas
 - Acute myeloid leukaemia
 - Brain

Patients deceased before January 1st 2017

Age at diagnosis ≥ 18 years

Exclusion Criteria

Patients with more than one invasive tumour (until 2015)

Patients without a Belgian residence

Patients without national social security number

Patients for whom no IMA data of the year of death were available (=3.9%)

Patients with an uncertain date of diagnosis

Maximum 3 years of follow-up

Analyses were limited to patients who died before January 1st of the third year following the year of incidence. For example: patients diagnosed in 2006 were included in case they died in 2006, 2007 or 2008; patients diagnosed in 2007 were included in case they died in 2007, 2008 or 2009, etc. These cohorts were defined in order to assure that for every diagnosis, the same follow-up period could be taken into account. By applying this definition, a bias induced by varying length of the follow-up period could be avoided.

Palliative care

Palliative care as identified in billing data includes patients receiving lump sum for palliative care at the usual place of residence, patients reimbursed for visits of the general practitioner or nurse within a palliative setting, patients hospitalized in palliative units or hospitalized patients reimbursed for visits of multidisciplinary palliative care teams.

Limitation

Real proportion may be underestimated as patients may receive palliative care without nomenclature codes being registered.

Cause of death is unknown: it is assumed that the patients died from the cancer, and hence required palliative care at the end of their life, but this is probably not the case for 100% of the patients (e.g. patients dying from other causes, patients requesting euthanasia).

No information on terminal patients apart from the oncology setting.

International comparability

This is not an international indicator. Some results are available in national reports or in specific scientific articles.

Dimensions

Accessibility



13.1.2. Results

Analysis of national data in cancer patients revealed that in 2015 on average more than half (53.4%) of the terminal cancer patients received palliative care. A slight increase in the use of palliative care services was seen compared to 2008 (48.0%) (see Table 118). A subanalysis by tumour type showed a higher proportion of acute tumour cancer patients receiving palliative care compared to cancer patients with chronic tumours (54.7% vs 44.0% respectively, see Table 118). Similar to the overall results, an increase over time was seen in both the groups (i.e. acute and chronic tumour type) cancer patients.

Detailed results by tumour type showed substantial differences in the use of palliative care within each broad category. For example, within the group of patients with acute tumours, the proportion of patients receiving palliative care ranged from 29.8% for acute myeloid leukaemia to 65.8% for brain cancer (see Table 119). Also, the proportion of patients receiving palliative care is generally lower in haematological tumours, both in acute and chronic types.

A higher proportion of cancer patients receiving palliative care was seen in the Flemish Region (59.8%) compared to the two other regions (43.7% in Brussels-Capital Region and 46.1% in the Walloon Region) (see Table 120)

Table 118 – Proportion of patients who received palliative care, by year of death (2008-2015) (maximum 3 years of follow-up)

	All Tumours			Acute Tumours			Chronic Tumours		
	Total	Receiving palliative care		Total	Receiving palliative care		Total	Receiving palliative care	
	N	n	%	N	n	%	N	n	%
2008	9 585	4 603	48,0	8 360	4 093	49,0	1 225	510	41,6
2009	9 462	4 543	48,0	8 233	4 024	48,9	1 229	519	42,2
2010	9 871	4 810	48,7	8 598	4 321	50,3	1 273	489	38,4
2011	9 936	4 982	50,1	8 745	4 500	51,5	1 191	482	40,5
2012	10 040	5 129	51,1	8 781	4 608	52,5	1 259	521	41,4
2013	10 087	5 176	51,3	8 864	4 658	52,5	1 223	518	42,4
2014	10 003	5 436	54,3	8 835	4 930	55,8	1 168	506	43,3
2015	9 838	5 257	53,4	8 634	4 727	54,7	1 204	530	44,0
Total	78 822	39 936	50,7	69 050	35 861	51,9	9 772	4 075	41,7

Note: To assure a same follow-up period for every patient included, deaths occurring in 2006 and 2007 were excluded. Deaths occurring in 2016 were also excluded, as no incidences were studied for that year.

Source: BCR linked to IMA data


Table 119 – Proportion of patients receiving palliative care by tumour type (all patients, maximum 3 years of follow-up) (2006-2015)

	Total	Receiving palliative care	
	N	n	%
Acute	84 602	43 493	51,4
• Oesophagus	4 967	2 326	46,8
• Stomach	7 014	3 440	49,0
• Liver, primary	3 995	1 992	49,9
• Gallbladder and biliary Tract	2 357	1 214	51,5
• Pancreas	10 298	6 149	59,7
• Lung, bronchus and trachea	47 365	23 628	49,9
• Pleura	1 703	1 073	63,0
• Brain	4 479	2 948	65,8
• Acute myeloid leukaemia	2 424	723	29,8
Chronic	11 890	4 892	41,1
• Head and Neck	5 034	2 114	42,0
• Small Intestine	655	304	46,4
• Nasal cavities and sinuses	363	192	52,9
• Ovary and uterine adnexa	3 068	1 544	50,3
• Multiple Myeloma	1 983	554	27,9
• Acute lymphatic leukaemia	238	65	27,3
• Chronic myeloid leukaemia	549	119	21,7
Total	96 492	48 385	50,1

Source: BCR linked to IMA data


Table 120 – Proportion of patients who received palliative care, by region (year of death=2015, incidence year 2006-2009 excluded)

	All Tumours			Acute Tumours			Chronic Tumours		
	Total	Receiving palliative care		Total	Receiving palliative care		Total	Receiving palliative care	
	N	n	%	N	n	%	N	n	%
Brussels-Capital Region	903	395	43,7	761	336	44,2	142	59	41,5
Flemish Region	6426	3840	59,8	5505	3375	61,3	921	465	50,5
Walloon Region	3996	1842	46,1	3328	1572	47,2	668	270	40,4
Total	11325	6077	53,7	9594	5283	55,1	1731	794	45,9

Source: BCR linked to IMA data

Note that as in the past patients were often recognized too late as palliative patient - often only a week before death – new criteria have been adopted which are no longer based on life expectancy but based on fragility. Previously the legally defined condition to be eligible for palliative care was a life expectancy of maximum three months. The new criteria are based on the first Palliative Care Indicator Tool (PICT) scale, in which the first question is “Would you be surprised if your patient would decrease in the coming 6 to 12 months?”.⁶ With this new definition, patients can be detected earlier on.

Note furthermore that the project on quality indicators for palliative care in Flanders developed 31 quality indicators on palliative care. As the implementation of the indicator set is limited to 29% of palliative care services in Flanders (37 teams), the data from this source have not been included in this report.⁷

Key points

- **Analysis of national data (2015) showed that more than half of the terminal cancer patients received palliative care. This percentage has slightly increased over time.**
- **Variation in palliative care measures exists among different tumour types. Hematological tumours appear to receive less palliative care compared to other tumour types.**

- **A higher proportion of cancer patients received palliative care in the Flemish Region (60%) compared to the Walloon (46%) and Brussels-Capital Region (44%).**
- **Data from abroad is lacking for international comparability.**

References

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13.2. Cancer patients who died within one week after start of palliative care (EOL-2)

13.2.1. Documentation sheet

Description	Cancer patients who started receiving palliative care and died within one week after start of palliative care
Calculation	Numerator: Number of patients who started palliative care and died within one week after start of palliative care Denominator: Total number of patients diagnosed with cancer that died in the studied time period and who received palliative care services
Rationale	The start of palliative care is sometimes postponed until patients are in a terminal phase of the disease. This can denote either problems of accessibility of end of life care, or that the decision on the start of palliative care was made too late.
Data source	Belgian Cancer Registry (BCR), linked with IMA data
Technical definitions	<p>It is currently not possible to identify all palliative patients in administrative databases or in registries. Therefore, the indicator has been restricted to patients diagnosed with cancer having a poor prognosis and deceased during the study period.</p> <p><u>Inclusion Criteria</u></p> <p>Incidence years: 2006-2015</p> <p>Tumour selection based on the Pallcare project ¹ : combination of topography and morphology according to Eurocare-4 ^{2 3}, and Eurocare-5 ⁴: see EOL-1</p> <p>Patients deceased before January 1st 2017</p> <p>Age at diagnosis ≥ 18 years</p> <p><u>Exclusion Criteria</u></p> <p>Patients with more than one invasive tumour (until 2015)</p> <p>Patients without a Belgian residence</p> <p>Patients without national social security number</p> <p>Patients for whom no IMA data of the year of death were available (=3.9%)</p> <p>Patients with an uncertain date of diagnosis</p>