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End-of-Life Care and Circumstances of Death in Patients Dying As a Result of Cancer in Belgium and the Netherlands: A Retrospective Comparative Study

KOEN MEEUSSEN, LIEVE VAN DEN BLOCK, MICHAEL A. ECHTELD, NICOLE BOFFIN, JOHAN BILSEN, VIVIANE VAN CASTEREN, EBUN ABARSHI, GÉ DONKER, BREGJE ONWUTEAKA-PHILIPSEN AND LUC DELIENS

ABSTRACT

Purpose To examine and compare end-of-life care in patients with cancer dying in Belgium and the Netherlands.

Patients and Methods A mortality follow-back study was undertaken in 2008 via representative nationwide sentinel networks of general practitioners (GPs) in Belgium and the Netherlands. By using similar standardized procedures, GPs reported on aspects of end-of-life care and the circumstances of nonsudden death of patients with cancer in their practice.

Results Of the 422 reported patients with cancer, most resided at home during the last year of life (Belgium, 91%; the Netherlands, 95%). Death occurred at home in 34% (Belgium) and 61% (the Netherlands) and in the hospital in 29% (Belgium) and 19% (the Netherlands). In the last month of life, end-of-life issues were more often discussed in the Netherlands (88%) than in Belgium (68%). In both countries, physical problems were discussed most often (Belgium, 49%; the Netherlands, 78%) and spiritual issues least often (Belgium, 20%; the Netherlands, 32%). Certain end-of-life treatment preferences were known for 43% (Belgium) and 67% (the Netherlands) of patients. In the last week of life, treatment was most often focused on palliation (Belgium, 94%; the Netherlands, 91%). Physical distress was reported in 84% (Belgium) and 76% (the Netherlands) of patients and psychological distress in 59% and 36%. Most distressing was lack of energy (Belgium, 73%; the Netherlands, 71%) and lack of appetite (Belgium, 61%; the Netherlands, 53%). Two thirds of patients were bedridden (Belgium, 67%; the Netherlands, 69%).

Conclusion Although place of death and communication about end-of-life issues differ substantially, a palliative treatment goal is adopted for the vast majority of patients in both countries. However, GPs reported that the majority of patients experienced symptom distress at the end of life, which suggests important challenges remain for improving end-of-life care.

INTRODUCTION

Cancer therapy is successful for many patients with cancer. However, in advanced cancer, cure or prolonging life may no longer be possible, and palliative care becomes the only realistic treatment option. Palliative care is aimed at improving the quality of life of patients and their families by providing relief from physical, psychological, and spiritual problems.¹ Although palliative care is well developed for patients suffering from cancer,² there is consensus that further improvement is still possible and needed.^{3,4}

Although large-scale studies demonstrate that many patients with cancer die at home,^{5,6} much information on end-of-life care and circumstances of dying for patients with cancer is often gathered from studies focusing on specific institutional care settings.⁷⁻¹³ To gain better insight into the care and the manner of dying of the total population of patients with cancer, nationwide studies irrespective of care setting or type of cancer are needed.

In both Belgium and the Netherlands, the existing nationwide representative networks of general practitioners (GPs) can be used to meet these goals. Since the provision of palliative care in both countries is often coordinated by the GP, almost all inhabitants have their own GP,^{14,15} and GPs are involved in end-of-life care in virtually all patients with cancer.¹⁶ This sentinel GP network has been used successfully in the past to study aspects of end-of-life care in both countries,¹⁷⁻²³ but studies have never focused specifically on patients dying as a result of cancer.

Identical study designs were used in both countries, which provides an important opportunity to perform cross-national comparisons. In both Belgium and the Netherlands, there is a high level of accessibility to general health care services and a policy of integration of palliative care into the national health care system,²⁴ but there are also important differences, making comparisons particularly relevant. Although Belgium has chosen to place multidisciplinary teams into different care settings, the Netherlands focuses more on the promotion of palliative care skills among regular caregivers supported by consultation teams.²⁵ GPs in the Netherlands act as absolute gatekeepers to more specialized care by being the patient's first contact with the health care system and controlling access and referrals to specialists' services and clinicians. In addition, there are specialized nursing homes in the Netherlands but not in Belgium.²⁶

The main objectives of this study are to describe the end-of-life care and circumstances of death of patients dying as a result of cancer in Belgium and the Netherlands and to make comparisons between the countries.

PATIENTS AND METHODS

Study Design

This study is an analysis of 1-year (2008) data collection within the Senti-Melc study, a study designed to monitor retrospectively the end of life of patients via existing national sentinel networks of general practitioners in Belgium and the Netherlands.²⁷ In both countries, these networks of GPs are reliable surveillance systems with a long history of nationwide surveillance of a wide variety of health-related topics that use similar standardized procedures of data collection.²⁷⁻³³ In the past, several of the registrations (eg, stroke mortality, suicide incidences, place of death, care setting trajectories) have been compared with data from external resources and have resulted in good external validity of the sentinel network's registrations.^{28,34-36}

In 2008, the Belgian network comprised 172 regularly participating practices compared with 45 in the Netherlands, each covering approximately 1% to 2% of the total registered patient population in each country and representative of GPs nationwide by sex, age, and geographic distribution.^{37,38}

Participating GPs were asked to fill in retrospectively a standardized registration form for all deaths at age 1 year or more in their practice covering the dying process and the care received during the last months of life. In Belgium, GPs reported deaths on a weekly basis; in the Netherlands, because GP patient lists are registered centrally, the registration form was sent to them by the Netherlands Institute of Health Services Research within 1 week of receipt of an electronic death notice. When necessary, reminders were sent.

Patients dying as a result of cancer were identified by a question about the underlying cause of death. Those who had died totally unexpectedly and suddenly, as judged by the GP, were excluded from further analysis since our focus was on those patients with cancer for whom the provision of end-of-life care was a relevant consideration.²⁰⁻²² All data were reported directly by the GP.

End-of-Life Care Setting and the GP

In both countries, the main settings for receiving end-of-life care and for dying are home, hospital, hospice or palliative care unit, and care home. In the Netherlands, there is a structural distinction between residential homes and nursing homes. Although both provide long-term home replacement care, residential homes provide basic assistance to older people who can no longer live independently under the care of the

GP, although nursing homes provide more specialized geriatric care by specialist nursing home physicians.³⁹ In Belgium, the GP is responsible for the care of both kinds of care home residents.²¹

Measurements

Several comprehensive conceptual frameworks on quality of end-of-life care exist, some specifically for patients with cancer.^{3,40-51} On the basis of these models, we identified the following key domains of end-of-life care: medical care processes, communication processes, and circumstances of dying (Table 1 provides an overview of the topics surveyed). Most questions had been developed and pretested in previous research.^{20,21,23,27,52-56}

[TABLE 1.]

Several procedures were used to ensure data quality: collective development and pretesting of the registration form in both countries, automatic follow-up (in Belgium), and telephone contact with the GPs to prevent missing data and ensure data entry with range, consistency, and skip checks. Methodologic details are described elsewhere.²⁷

Data Analysis

Percentages were used to describe the proportion of patients with cancer for whom different aspects of end-of-life care were provided. Fisher's exact tests were used to determine which aspects of the dying process or the care received at the end-of-life were associated with residing in either Belgium or the Netherlands ($P < .05$). Associations were further explored in multivariate logistic regression analyses while adjusting for differences in place of death (because of the relationship with GP involvement and country), age, and sex, unless stated otherwise. Possible interaction effects were determined between these patient characteristics and the patient's country. In the tables, we display the odds ratios (ORs) in cases in which a relevant country effect was found.

To investigate the representativeness of the data for all nonsudden cancer deaths in Belgium and the Netherlands, we compared age, sex, and place of death of our sample with numbers identified in previous nationwide representative death certificate studies in both Belgium (Flanders; comparison data were not available for the French-speaking part of Belgium)⁵⁷ and the Netherlands.⁵⁸ In Belgium, no significant differences between studies were found for these characteristics (multinomial 95% CI). In the Dutch part of the sample, nursing home deaths were underrepresented, which was to be expected since nursing home physicians take over care from the GP. After leaving out these deaths, representativeness was reached. We used SPSS 17 (SPSS, Chicago, IL) and StatXact6 (Cytel Studio, Cambridge, MA) for statistical computations.

RESULTS

Characteristics of Patients

The Belgian and Dutch GPs reported 1,354 and 405 deaths, respectively. We excluded all patients who had died suddenly (35%; $n = 616$) leaving 1,143 patients. For 422 of these (37% in each country), cancer was reported as the underlying cause of death. The majority of patients in both countries resided at home during the last year of life (Belgium, 95%; the Netherlands, 91%; Table 2). Place of death was the only characteristic that was strongly associated with country ($P < .001$), with more hospital deaths in Belgium (29% v 19%) and more deaths at home in the Netherlands (59% v 34%).

[TABLE 2.]

Medical Care Processes at the End of Life

During the last 3 months of life, 38% of Belgian and 56% of Dutch patients had more than eight contacts with their GP ($P = .001$; Table 3); 66% of Belgian and 44% of Dutch patients were transferred to another care setting ($P < .001$), and 72% of Belgian and 34% of Dutch patients used palliative care services ($P < .001$).

[TABLE 3.]

During the last week of life, contact with the GP was maintained by 71% of Belgian and 87% of Dutch patients ($P = .001$), and the treatment goal was palliation and not cure or prolonging life in 94% of Belgian and 91% of Dutch patients ($P = .372$).

Multivariate analyses showed that variations in the use of palliative care services (more in Belgium; OR, 6.73), the proportion of patient-GP encounters in the last week of life (more in the Netherlands; OR, 0.48), and hospital deaths (more in Belgium; OR, 1.89) remained statistically significant after controlling for differences in patient characteristics.

Communication Processes at the End of Life

Before the last month of life, 74% (Belgium) and 71% (the Netherlands) of patients who died as a result of cancer had discussed one or more end-of-life care issues with their GP ($P = .695$; Table 4). Primary diagnosis, incurability of the illness, and physical symptoms were discussed most frequently in both countries, and spiritual issues were discussed least frequently.

[TABLE 4.]

During the last month of life, 68% (Belgium) and 88% (the Netherlands) of patients had discussed one or more end-of-life care issues with their GP ($P < .001$). In Belgium, less than a third had talked about spiritual issues, social problems, the burden of treatments, primary diagnosis, possible medical complications, or life expectation. Other issues were discussed more often but never by more than half the patients. In the Netherlands, only discussion of spiritual issues was rare, whereas all other topics were discussed by at least half the patients and most frequently concerned life expectation, options for palliative care, and physical problems. All differences between countries, except for spiritual issues, remained significant in the multivariate analyses after controlling for differences in age, sex, and place of death. After additionally adjusting for number of patient contacts during the last month of life (to evaluate whether contact frequency would explain differences in communication), significance was maintained.

About half (54%) of Belgian and 73% of Dutch patients expressed a preference for place of death ($P = .001$), and 43% of Belgian and 67% of Dutch patients had at some point expressed a wish concerning medical end-of-life treatment ($P < .001$). After adjustment for differences in age, sex, and place of death, country remained associated with the prevalence of a preference for end-of-life treatment (more in the Netherlands; OR, 0.40).

Circumstances of Dying

During the last week of life, about two thirds of patients with cancer in Belgium (67%) and the Netherlands (69%) were completely physically disabled and bedridden ($P = .712$; Table 5). Physical distress was reported in 84% of the patients in Belgium and in 76% in the Netherlands ($P = .138$) and psychological distress in 59% and 36%, respectively ($P < .001$). As judged by the GP, the most distressing symptoms were lack of energy (Belgium, 73%; the Netherlands, 71%) and lack of appetite (Belgium, 61%; the Netherlands, 53%). The difference in psychological distress, as judged by the GPs, remained after adjustment for differences in sex, age, and place of death (OR, 2.66). We additionally controlled for the occurrences of patient contact in the last week of life and prevalence of communication about psychological problems in the last month of life as possible confounders, but this did not alter the results.

[TABLE 5.]

Congruence between the preferred and actual place of death was reached in 71% of Belgian and in 88% of Dutch patients ($P = .004$). The chances of dying in the place of choice were three times lower in Belgium than in the Netherlands (OR, 0.31).

DISCUSSION

In both countries, more than 90% of patients were able to live at home for most of the time during their last year of life, had a palliative treatment goal in the last week of life, and discussed one or more end-of-life issues with their GP during the last months of life. During the last week of life, two thirds of patients

were bedridden, and the majority experienced distress from at least one physical symptom. Several aspects of care and dying were found to be related to country.

Data were collected via existing representative national GP networks to provide a nationwide general practice cancer population irrespective of care setting. The networks had been operational for many years and were registering a wide variety of health-related problems before end-of-life care was added. Other strengths of the study include the quality of the data collection procedures²⁷ and the fact that the 2008 registration form used was developed simultaneously and in close collaboration between countries specifically for the purpose of cross-national comparability.

The study has several limitations. First, a retrospective study design may induce some bias. GPs might have overestimated some aspects of their caregiving (eg, the level of communication) or underestimated some aspects (eg, symptom distress) because of their awareness of what is socially desirable or of the difficulties of making a retrospective judgment of their own intentions, and these tendencies might differ between countries; however, most of the questions relate to an objective description of the patient's last phase of life. GPs may also have lacked the required information or recalled it incorrectly or did not consult the patient's medical record. The chances of this were reduced by the collection of data on a weekly basis, leaving little time between death and registration, and by instructing the GP to use patient files as much as possible. Second, some bias due to a GP's particular interest cannot be entirely excluded. Third, full nationwide representativeness could not be guaranteed in the Netherlands for nursing home deaths because GPs are not involved in care in these settings. However, given the high involvement of the GP in end-of-life care in both countries,¹⁴⁻¹⁶ the largely non-cancer population in Dutch nursing homes,^{39,59-61} the adjustment for place of death in our analyses, and the representativeness of the sample (if nursing home deaths are excluded), the results provide valuable insights into the manner in which the general population of patients with cancer die in Belgium and the Netherlands.

The results of this study show similarities as well as differences between the end of life of patients with cancer in Belgium and the Netherlands. Notwithstanding that more than 90% of patients were able to live at home for most of the time during the last year of life in both countries, a substantial proportion in both Belgium (29%) and the Netherlands (19%) die in a hospital. As we know, terminally ill patients with cancer prefer to be cared for at home and also to die there⁶²⁻⁶⁴; hence, the latter result might be a cause for concern for both practice and policy. However, the problem of death in a hospital seems most obvious in Belgium, and the contrast might be related to government and palliative care policies that, in the Netherlands, are more clearly geared toward encouraging death at home^{5,60} and also to differences between primary care cultures. In both countries, GPs occupy a prominent position in the provision of palliative care,^{26,65} but their specific roles at the end of life are different. Being gatekeepers to the health care system, Dutch GPs take on most care tasks themselves, although Belgian GPs seem more often to pursue a coordinating role only.^{25,26,66} This hypothesis is further supported by the finding that palliative care services are more likely to be used in general practice in Belgium than in the Netherlands, and by the differences in numbers of patient contacts in the last phase of life, especially during the last week.

The higher prevalence of end-of-life patient-GP conversations during the last month of life in the Netherlands compared with Belgium might also be related to the differences in medical culture. Ideas of candor and open communication might be valued more highly in the Netherlands,²⁶ which could also partly explain the variation in the GP's knowledge of their patients' preferences about medical end-of-life treatment (43% in Belgium v 67% in the Netherlands).

Notwithstanding these differences, there are several similarities as well. In both countries, GPs focus more on physical and psychological than on spiritual or social issues; it may be that GPs feel less comfortable in introducing these topics, that other professionals may fulfill this task, or that these issues do not concern patients as much as others do. Options for palliative care were principally discussed during conversations held in the last month of life rather than earlier when the subject was addressed by fewer than half the patients; this is somewhat surprising, given the strong emphasis the palliative care movement places on advocating early communication and advance care planning and the relatively predictable disease trajectory of patients with cancer.^{2,67,68}

From its beginnings, palliative care has predominantly focused on cancer care, and our results show the deep penetration of palliative care into end-of-life care for patients with cancer in both of the countries studied.¹ Although a palliative care approach was present for most patients, many experienced symptom distress at the very end of life. Lack of energy and lack of appetite occurred as the most distressing physical

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symptoms in a majority of patients. Pain was reported far less often as having caused distress, which might indicate that pain is a symptom that can be alleviated by palliative care, although other symptoms are far more challenging. However, pain was still a distressing symptom in more than 20% of patients with cancer in both countries, which suggests that there is potential for improvement in alleviating pain at the end of life.

In conclusion, the use of a nationwide sentinel network of GPs can provide important insights into how patients with cancer in general are dying in a particular country. It can also make comparison between countries possible. Although place of death and communication on end-of-life issues differ substantially between Belgium and the Netherlands, a palliative treatment goal has been adopted for the vast majority of patients in both countries. However, GPs report that the majority of patients with cancer still experience symptom distress at the end of life, which suggests important challenges for improving end-of-life care. Future research should also address other important aspects in the provision of end-of-life care, such as the well-being of families, and it should study more deeply the cause and effect of different health care approaches and their outcomes.

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- Authors' disclosures of potential conflicts of interest and author contributions are found at the end of this article.

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TABLES

Table 1. Important Domains in End-of-Life Care Assessed in This Study
<p>Medical care processes at the end of life</p> <p>Number of general practitioner (GP)-patient encounters in the final 3 months of life (or encounters between GP and patient's relatives, regarding the patient)</p> <p>Transitions, if any, between care settings in the final 3 months of life</p> <p>In case of hospital death, the moment of admission</p> <p>Patient's main treatment goal in the last week of life (cure, prolonging life, palliation)</p> <p>Involvement of specialist palliative care services. In the Netherlands: a GP with palliative care training, team with a palliative care consultant (trained nurse or physician), hospital-based palliative units, nursing home-based palliative care units, and hospice day care facility. In Belgium: multidisciplinary palliative support home care teams, hospital-based mobile support teams, hospital-based palliative care units, palliative day care centers, and care home-based palliative care reference nurses</p> <p>Palliative care services were considered to have been used if at least one service had been used during the last 3 months of life</p>
<p>Communication processes at the end of life</p> <p>Content of the GP-patient conversations in the last month of life and before (about primary diagnosis, incurability of illness, life expectation, possible medical complications, physical symptoms, psychological problems [eg, sadness, worry, fear], social problems [eg, relationship problems, lack of social support, family not accepting the situation], spiritual problems [eg, difficulty in accepting situation, trouble with the meaning of life, angry at God], options for palliative care, burden of treatments)</p> <p>Whether the patient had ever expressed wishes about any medical treatment that he or she would or would not want in the final phase of life and about the place of death</p>
<p>Circumstances of dying</p> <p>Functional status during the last week of life using the Eastern Cooperative Oncology Group (ECOG) performance status scale: 0, fully active; 1, ambulatory, capable of work of a light nature; 2, capable of self-care but not work; 3, in bed \geq 50% of the time, capable of only limited self-care; 4, completely bedridden, incapable of self-care</p> <p>Whether the patient was in a coma or unconscious until death and, if so, for how long. Physical and psychological symptom distress during the last week of life was measured by the Memorial Symptom Assessment Scale-Global Distress Index (MSAS-GDI). GPs were asked whether the patient had the following symptoms during the last week of life (yes, no, unknown): lack of appetite, lack of energy, pain, feeling drowsy, constipation, dry mouth, difficulty breathing (physical symptoms); feeling sad, worrying, feeling irritable, feeling nervous (psychological symptoms). If yes, GPs were asked how much symptom distress the patient experienced (not at all, a little bit, somewhat, quite a bit, very much, unknown) for physical symptoms and how often a symptom occurred (rarely, occasionally, frequently, almost constantly, unknown) for psychological symptoms</p> <p>Psychological symptoms were considered to have caused distress if patients appeared to feel this way "frequently" or "almost constantly" during the last week of life. Physical symptoms were considered to have caused distress if symptoms distressed the patient "quite a bit" or "very much." Symptoms that were not present were considered to have caused no distress. The GDI was calculated as the mean of the item scores for all physical and psychological symptoms; patients for whom no answer was given on more than three symptom items were not included in this calculation⁵⁵</p> <p>Whether the patient died at the place wished</p>



Table 2. Characteristics of the Study Population

Characteristic	All Cancer Deaths (N = 422)		Belgium (n = 321)		The Netherlands (n = 101)		P*
	No.	%	No.	%	No.	%	
Age, years							
≤ 64	120	28.7	87	27.4	33	32.7	.381
65-79	156	37.3	117	36.9	39	38.6	
80+	142	34.0	113	35.6	29	28.7	
Mean	71.7		72.2		70.4		.247
Sex							
Male	226	53.7	173	54.1	53	52.5	.819
Female	195	46.3	147	45.9	48	47.5	
Educational level							
Elementary school/elementary or middle school (approximate age, ≤ 12 years)	129	33.7	92	32.1	37	38.5	.465
Middle school or high school	202	52.7	156	54.4	46	47.9	
College/university	52	13.6	39	13.6	13	13.5	
Longest place of residence in last year							
Home or with family	382	92.0	287	91.1	95	95.0	.289
Care home	33	8.0	28	8.9	5	5.0	
Elsewhere (n = 6)†							
Place of death							
Home or with family	169	40.0	109	34.0	60	59.4	< .001
Care home‡	48	11.4	38	11.8	10	10.0	
Hospital	113	26.8	94	29.3	19	18.8	
Hospice/palliative care unit	87	20.6	78	24.3	8	8.9	
Elsewhere†	5	1.2	2	0.6	3	3.0	

NOTE. Missing values for age at death, n = 4; sex, n = 1; level of education, n = 39; longest place of residence, n = 1.
 *Fisher's exact test or t test for equality of means to test differences between patients with cancer dying in Belgium and the Netherlands.
 †Not included in statistical analysis.
 ‡Care homes or residential homes for older people (n = 43); nursing homes (n = 5).

Table 3. Characteristics of Medical Care Processes at the End of Life

Characteristic	All Cancer Deaths (N = 422)		Belgium (n = 321)		The Netherlands (n = 101)		Fisher's Exact P	OR*	95% CI
	No.	%	No.	%	No.	%			
During the last 3 months of life:									
More than eight GP-patient contacts†	179	42.4	122	38.0	57	56.4	.001	0.62	0.37 to 1.02
Transferred at least once between care settings	250	61.1	209	66.3	41	43.6	< .001	1.75	0.93 to 3.27
Palliative care services initiated	265	62.9	231	72.0	34	34.0	< .001	6.73	3.86 to 11.75
During last week of life:									
One or more GP-patient contacts	316	74.9	228	71.0	88	87.1	.001	0.48	0.23 to 0.996
Transferred at least once between care settings	82	20.0	70	22.2	12	12.8	.056	1.52	0.71 to 3.28
Terminal hospital admission	113	26.8	94	29.3	19	18.8	.040	1.89‡	1.08 to 3.30
Admission during last week (v before last week)	38	34.9	32	34.8	6	35.3	1.000	1.01	0.33 to 3.03
Palliative treatment goal (v curative/prolonging life)	385	93.0	294	93.6	91	91.0	.372	1.92	0.77 to 4.77

NOTE. Missing values for transfer between care setting, n = 13; timing of terminal hospital admission, n = 9; treatment goal, n = 8; specialist palliative care services involved, n = 1.

Abbreviations: GP, general practitioner; OR, odds ratio.

*From multivariate logistic regression models. For these analyses, we compared end-of-life care between patients with cancer from the Netherlands (reference category) and those from Belgium while adjusting for differences in place of death, age, and sex.

†Dichotomized at its median value; the two groups differ in size because approximately 10% of patients had the median number of eight GP contacts.

‡Not controlled for place of death in multivariate analysis.

Table 4. Characteristics of Communication Processes at the End of Life

Characteristic	All Cancer Deaths (N = 422)		Belgium (n = 321)		The Netherlands (n = 101)		Fisher's Exact P	OR*	95% CI
	No.	%	No.	%	No.	%			
GP-patient conversations									
Prior to last month of life, about:									
Primary diagnosis	239	58.4	192	60.8	47	50.5	.094	1.71	1.04 to 2.82
Incurability of illness	213	51.7	157	49.7	56	58.3	.162	0.73	0.45 to 1.19
Life expectation	170	41.5	127	40.3	43	45.3	.407	0.92	0.56 to 1.50
Possible medical complications	178	43.5	136	43.3	42	44.2	.906	1.01	0.62 to 1.65
Physical symptoms	240	58.3	187	59.2	53	55.2	.555	1.23	0.76 to 2.00
Psychological problems	175	42.8	134	42.8	41	42.7	1.000	1.13	0.69 to 1.84
Social problems	128	31.4	101	32.4	27	28.4	.529	1.21	0.71 to 2.05
Spiritual problems	77	19.2	61	19.8	16	17.0	.654	1.34	0.70 to 2.53
Options for palliative care	147	35.8	106	33.8	41	42.3	.146	0.67	0.41 to 1.09
Burden of treatments	179	43.4	143	45.3	36	37.5	.197	1.53	0.93 to 2.52
One or more of these topics was discussed	302	72.9	233	73.5	69	71.1	.695	1.22	0.72 to 2.08
During the last month of life, about:									
Primary diagnosis	155	37.9	98	31.0	57	61.3	< .001	0.34	0.21 to 0.56
Incurability of illness	174	42.2	107	33.9	67	69.8	< .001	0.28	0.17 to 0.46
Life expectation	169	41.2	100	31.7	69	72.6	< .001	0.22	0.13 to 0.37
Possible medical complications	151	36.9	98	31.2	53	55.8	< .001	0.43	0.26 to 0.70
Physical symptoms	231	56.1	156	49.4	75	78.1	< .001	0.35	0.20 to 0.60
Psychological problems	207	50.6	140	44.7	67	69.8	< .001	0.42	0.25 to 0.70
Social problems	139	34.2	90	28.8	49	51.6	< .001	0.46	0.28 to 0.75
Spiritual problems	91	22.6	61	19.8	30	31.9	.017	0.68	0.39 to 1.18
Options for palliative care	215	52.3	144	45.9	71	73.2	< .001	0.40	0.24 to 0.67
Burden of treatments	153	37.1	98	31.0	55	57.3	< .001	0.40	0.24 to 0.65
One or more of these topics was discussed	299	72.2	214	67.5	85	87.6	< .001	0.37	0.19 to 0.72
End-of-life preferences									
Patient ever expressed preference									
For place of death	219	59.0	150	54.2	69	73.4	.001	0.63	0.34 to 1.15
About a medical end-of-life treatment	184	48.8	119	42.5	65	67.0	< .001	0.40	0.23 to 0.67

NOTE. Missing values on communication < 5%; missing values or indicated by the general practitioner (GP) as unknown for treatment preferences, n = 45; for preference for place of death, n = 51.

Abbreviation: OR, odds ratio.

*From multivariate logistic regression models. For these analyses, we compared end-of-life care between patients with cancer from the Netherlands (reference category) and those from Belgium while adjusting for differences in place of death, age, and sex.

Table 5. Circumstances of Dying

Variable	All Cancer Deaths (N = 422)		Belgium (n = 321)		The Netherlands (n = 101)		Fisher's Exact P	OR*	95% CI
	No.	%	No.	%	No.	%			
Clinical status in last week of life									
Physically completely disabled and bedridden†	275	67.1	209	66.6	66	68.8	.712	0.97	0.59 to 1.62
One or more days unconsciousness until death	214	56.0	171	58.0	43	49.4	.177	1.26	0.76 to 2.08
Physical symptom distress in last week of life									
GP could make estimation‡	362	85.8	282	87.9	80	79.2	.034	3.58	1.76 to 7.13
Distress from at least one symptom	297	82.0	236	83.7	61	76.3	.138	1.59	0.84 to 3.02
Lack of appetite	207	59.3	165	61.1	42	53.2	.241	1.22	0.72 to 2.08
Lack of energy	254	72.8	197	73.2	57	71.3	.775	1.09	0.61 to 1.96
Pain	80	23.2	61	23.0	19	23.8	.881	0.98	0.52 to 1.87
Feeling drowsy	98	28.9	82	31.7	16	20.0	.049	1.77	0.92 to 3.39
Constipation	34	11.0	29	12.7	5	6.3	.147	2.37	0.85 to 6.64
Dry mouth	63	20.4	52	22.5	11	14.1	.143	1.59	0.75 to 3.37
Difficulty breathing	86	25.3	74	28.5	12	15.0	.018	2.14	1.04 to 4.39
Psychological symptom distress in last week of life									
GP could make estimation‡	322	76.3	244	76.0	78	77.2	.893	0.35	0.10 to 1.22
Distress from at least one symptom	172	53.4	144	59.0	28	35.9	<.001	2.66	1.49 to 4.77
Feeling sad	102	34.1	88	38.9	14	19.2	.002	2.57	1.29 to 5.13
Worrying	121	39.9	101	44.3	20	26.7	.007	1.98	1.05 to 3.73
Feeling irritable	41	13.4	37	15.9	4	5.3	.019	3.85	1.28 to 11.58
Feeling nervous	61	20.3	56	24.7	5	6.8	.001	4.66	1.74 to 12.48
Global Distress Index (mean)	1.25		1.32		1.04		.001	2.97	1.62 to 5.50
Died at the place of wish§	167	76.3	106	70.7	61	88.4	.004	0.31	0.14 to 0.71

NOTE. Additional missing values on symptom distress vary between n = 13 and n = 54; missing values for performance status, n = 12; for unconsciousness, n = 40.
Abbreviations: GP, general practitioner; OR, odds ratio.
*From multivariate logistic regression models. For these analyses, we compared end-of-life care between patients with cancer from Netherlands (reference category) and those from Belgium while adjusting for differences in place of death, age, and sex.
†Eastern Cooperative Oncology Group (ECOG) performance status scale: 0, fully active; 1, ambulatory, capable of work of a light nature; 2, capable of self-care but not work; 3, in bed ≥ 50% of the time, capable of only limited self-care; 4, completely bedridden, incapable of self-care. Figures in this row are % of patients for whom grade 4 (v 0 to 3) was assigned.
‡For at least one symptom.
§GP was informed by patient about the preferred place of death; variables controlled for in multivariate analysis: age, sex, longest place of residence.