

## ORIGINAL ARTICLE

# Cancer care near the end-of-life in Austria: A retrospective data analysis

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**Abstract**

**Objective:** Since end-of-life care (EOL) is an internationally accepted indicator for the quality of oncological care we aimed to investigate the current EOL care situation for Austrian cancer patients especially concerning the place of death cancer treatment hospitalisation near death and palliative care.

**Methods:** A retrospective data analysis was carried out based on Austrian routine inpatient data of the years 2012 to 2016. Data including the date of death of adult patients with a main hospital discharge diagnosis of a neoplasm were included. All analyses were source-related and based on the place of residence.

**Results:** In total 80818 cancer patients have died between 2012 and 2016 of whom 53.4% died in the inpatient setting. Palliative care at the EOL (last hospitalisation) was present in 12.9% of patients whereby more than 50% were admitted two to 14 days before death. Considering cancer treatment at the EOL (30 days before death) 6.9% of cancer patients have received chemotherapy 1.7% radiation therapy and 0.75% were treated with a monoclonal antibody.

**Conclusion:** In international comparison Austria appears to do well on quality indicators concerning ICU-admission and chemotherapy treatment average on hospital death and poorly on hospital admissions and timely referral for palliative care.

**KEYWORDS**

aggressive treatment, end-of-Life care, oncology, quality indicators, quality of cancer care, systemic cancer care

## 1 | INTRODUCTION

Aggressive cancer treatment near the end-of-life (EOL) has been identified as a lack of quality of cancer care since long (Wild & Patera 2013). Most western countries have embedded in their respective national cancer plans or roadmaps some strategies to use routine data for analysing the quality of care. Quality indicators enable the evaluation of the appropriateness of EOL within a health care system (De Schreye et al. 2017; Earle et al. 2003). Hence they can support the improvement of health care along the continuum of interventions by early detection coordination of multimodal regimes

or providing symptomatic (palliative) care (De Roo et al. 2013; Earle et al. 2003). Quality indicators in the area of cancer care encompass 'amount of inpatient deaths' 'extensive use of systemic chemotherapy at the EOL' 'admission to intensive care units (ICUs) and hospitalisations at the EOL' or 'lack of referral to palliative care units' (De Schreye et al. 2017; Earle et al. 2003 2008; Henson et al. 2020; Wild & Patera 2013).

Within the latest of such strategic cancer plans the 'Europe's Beating Cancer plan' (European Commission (EC) 2020) has been introduced. Herein the best possible quality of life for cancer patients should be 'ensured by platforms structures and resources that

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support the dissemination of best practices on issues such as psychological support pain management professional re-integration and by filling knowledge gaps with data analysis and science evidence'. Although the monitoring of the quality of care at the EOL is not directly explicitly expressed in the EC-Cancer plan the Austrian cancer framework programme introduced in 2014 formulated the goal of 'high-quality data' as an important element for health care research monitoring the actual care for cancer patients (Bundesministerium für Gesundheit (BMG) 2014).

Within this context the Austrian Institute for Health Technology Assessment (AIHTA) former Ludwig Boltzmann Institute for HTA (LBI-HTA) has launched several health care research projects in oncology of which one is presented here (Robausch & Grössmann 2020). For Austria Fuchs et al. (Fuchs & Robausch 2018) had already published results regarding health care indicators to assess the EOL care of cancer patients for one region (Lower Austria) in 2018. The present work aims to reproduce these results for all nine regions in Austria to expand them (longer period) and to study regional variability inspired by the NHS Atlas of Variation in Healthcare (Public Health England 2018). In addition a comparison with international reference values should also be made.

## 2 | METHODOLOGY: DATA BASIS VALIDATION AND ANALYSIS

The methodology is based on analyses of two research projects that were recently conducted by the AIHTA (Grössmann et al. 2020; Robausch & Grössmann 2020). All adult patients aged 18 years or older with a main hospital discharge diagnosis of a neoplasm (International Classification of Disease 10th Revision [ICD-10]: C00-C97) were eligible for our analyses. In addition patients had to have an officially registered residence in Austria. Data of all patients comprising the date of death that have been diagnosed with an oncological disease in a publicly funded Austrian hospital were included. The defined observation period was between 01.01.2012 and 31.12.2016 (data from 5 years). The analyses were source-related and based on the place of residence of the patients identified by the cancer diagnoses that were documented during their inpatient stays. Generally routine data were analysed using the R environment as well as Microsoft Office Excel 2016 for data presentation (R Core Team 2015).

For the retrospective data analyses Austrian routine inpatient data from the Main Association of Austrian Social Insurance Institutions was used. Therefore the following insurance funds as of 2019 which cover about 90% of the Austrian population were included: the nine Regional Social Health Insurance Funds (GKK) the Insurance Institution for Farmers (SVB) the Insurance Institution for self-employed businesses (SVA) the Insurance Institution for Public Servants (BVA) and the Insurance Institution for the Austrian Railways and Mining Industry (VAEB). However since different (incompatible) database systems are in place in the case of the Company Health Insurance Funds and the Health Care Institution

of the Municipal Civil Servants (~10% of the Austrian population) these could not be included. Besides in the hospital outpatient care setting the documentation of applied interventions had become mandatory in 2014. However the data quality was insufficient for our analyses.

Austrian inpatient routine data are mainly based on four categories:

- information on *hospital stays* including data on the personal ID date of hospital admission and discharge number of hospital days citizenship;
- *patient* information like the birth year date of death residential district as well as sex;
- *diagnoses* with at least one main diagnosis and any number of additional diagnoses as well as the respective ICD-10 category;
- type and number of *hospital services* according to the Austrian hospital benefit catalogue.

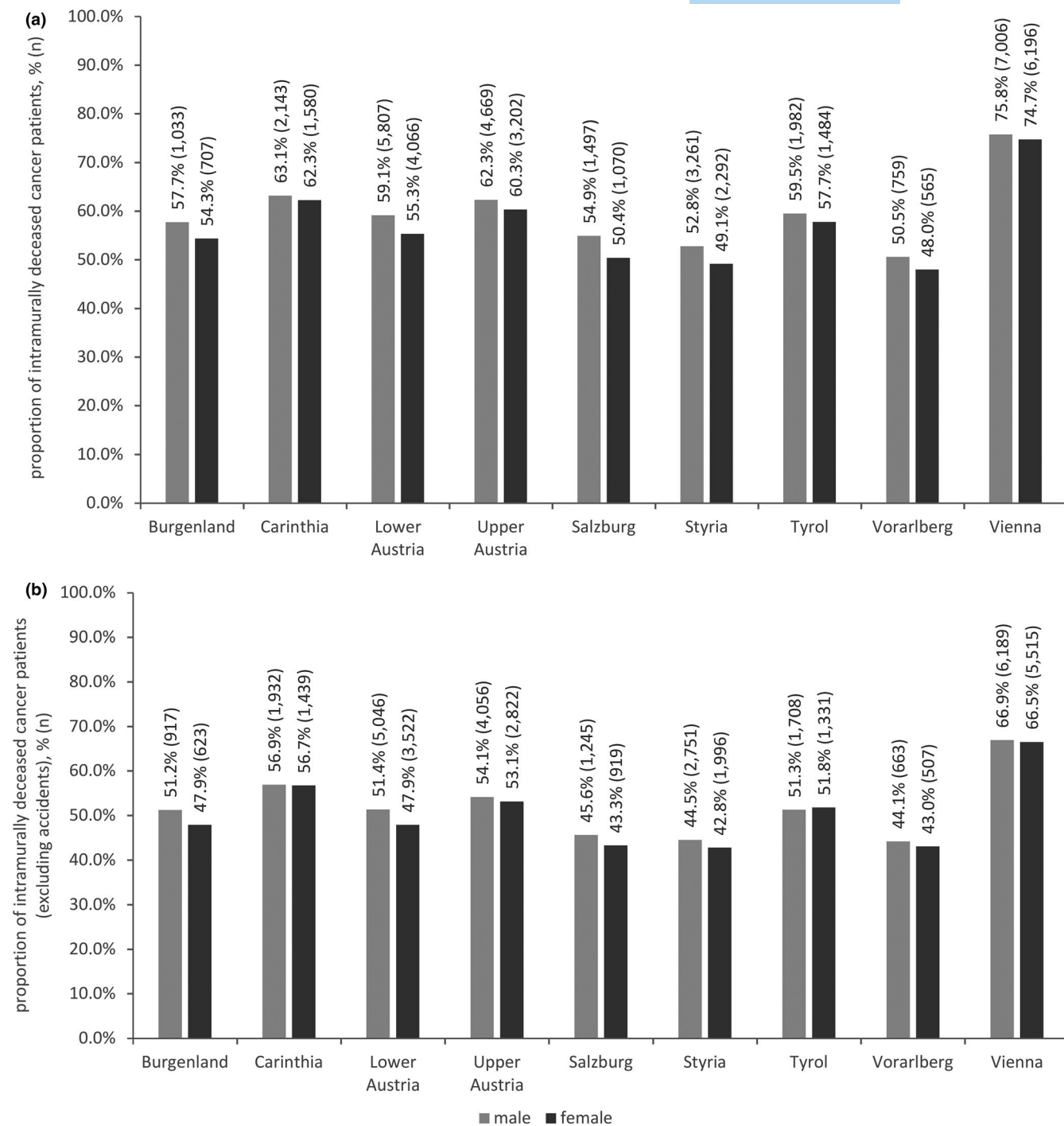
To pseudonymise our data all patients were coded with a consecutive study ID number. Therefore each patient received an internal ID (hash value) from a distinctive personal identifier calculated from the source of information (social security number). The data were stored with restrictive access (MR NG employees of DEXHELPP) at an independent project-specific research server (Verein DEXHELPP zur Forschungsförderung im Gesundheitssystem). Validation of data for plausibility was performed internally (based on consistency) and on an external level in cooperation with the Austrian Public Health Institute (GÖG). The external validation was mainly focusing on the prevalence of diagnosed inpatient cancer cases during our observation period.

## 3 | RESULTS

During the observation period (2012–2016) 283228 patients with cancer diagnoses were admitted to a publicly funded hospital. Of these 28.5% (80818) persons have died of whom 43.7% ( $n = 35331$ ) were female and 56.3% ( $n = 45487$ ) were male. Considering the number of deaths concerning the total prevalence of each sex a mortality rate of 25.5% (women) and 31.5% (men) could be identified. The average age of the deceased persons who were diagnosed with cancer during our observation period was 69.0 (20 - >90) years for women and 69.8 (19 - >90) years for men whereby most cancer patients were 75 to 79 years old.

### 3.1 | Intramurally deceased cancer patients

In total 49319 cancer patients (28157 men 21162 women) died in a publicly funded Austrian hospital. This corresponds to a proportion of 60.8% (61.9% men 59.9% women) of all deceased cancer patients. Across all nine Austrian federal states the proportions of intramurally deceased cancer patients were ranging from 50.4% to 75.8% with highest values in Vienna (75.8% men 74.7% women; Figure 1).



**FIGURE 1** (a) proportion of cancer patients who have died in a publicly funded Austrian hospital. (b) proportion of intramurally deceased cancer patients excluding accidents

Proportions of female cancer patients were generally lower in all federal states. Considering the age of the deceased cancer patients higher percentages of intramural deaths could be observed in the younger population (<65 years: ~70% vs. ≥65 years: ~59%).

In a second step we excluded all deceased cancer patients in whom the main or secondary hospital diagnosis (ICD 10: S00-T98) was indicating an accident as a reason for death. Hence on a national level the proportion of patients who have died intramurally was reduced from 60.8% to 53.4% (53.9% men 52.9% women). Highest

proportions were still observable in Vienna (66.9% men 66.5% women) as well as the distribution of age was comparable.

### 3.2 | Hospitalisation at the end-of-life

In total 55798 (69.0%) of all deceased cancer patients ( $n = 80818$ ) have been hospitalised 30 days before their death (Figure 2). Thirty-one per cent ( $n = 25020$ ) of patients have been hospitalised

more than 30 days before death 22.2% ( $n = 17928$ ) 15 to 30 days more than one third ( $n = 27711$  34.3%) 3 to 14 days and 12.6% ( $n = 10159$ ) two days before death. In general the proportion of hospitalised male cancer patients was higher than for female cancer patients. Across the nine federal states comparable percentages could be observed. Besides out of the 55798 persons who have been hospitalised 30 days before death a total of 6973 (12.5%) cancer patients were treated in an intensive care unit (ICU). The sex ratio was about 61.7% men ( $n = 4303/6973$ ) and 38.3% women ( $n = 2670/6973$ ). In comparison considering the total study population ( $n = 6973/80818$ ) 8.6% of patients were admitted to an ICU before death.

### 3.3 | Palliative care at the end-of-life

Concerning the proportion of persons whose last hospital stay before death was in a palliative care unit considerable variations between the federal states could be observed (Figure 3). The overall proportion in Austria was 12.9% ( $n = 10451/80818$ ); substantially lower proportions were present in Vorarlberg (5.7% male 6.5% female) and Lower Austria (6.5% male 8.0% female). In contrast highest proportions could be observed in Styria (17.0% male 20.0% female) and Carinthia (17.4% male 19.0% female). Generally higher percentages were present for female cancer patients.

Out of the 10451 cancer patients who have been admitted to a palliative care unit 8146 (77.9%; 4273 men 3873 women) persons died during their hospitalisation. The proportions of patients were homogenous across federal states with higher numbers compared with the Austrian average in Tyrol ( $n = 810/935$  86.6%) and Vienna ( $n = 2117/2385$  88.8%). Considering the number of days from admission to a palliative care unit until death we could see that the majority of the 8146 deceased persons were admitted 8 to 14 days

( $n = 2307/8146$  28.3%) followed by ( $n = 1915$  23.5%) 2 days before death and 15 to 30 days ( $n = 1770$  21.7%).

### 3.4 | Cancer treatments within 30 days before death

Considering cancer treatments during a hospital stay within 30 days before death slight variations could be observed comparing the Austrian federal states (Table 1). Thirty days before death 6.9% ( $n = 5580/80818$ ) of the Austrian cancer patients have received chemotherapy of whom 3327 (7.3%) were male and 2253 (6.4%) were female patients (Table 1). Highest proportions were observable in Salzburg with 506 (10.4%; 281 male 225 female) out of 4852 deceased patients who have received chemotherapy within 1 month before death. In contrast lowest proportions were present in Vorarlberg ( $n = 142/2680$  5.3%) and Burgenland ( $n = 167/3091$  5.4%).

In total 1344 patients (1.7%; male 833 511 female) have received a radiation therapy 30 days before death. The proportions for male patients were generally higher compared with female patients across federal states (1.8% vs. 1.5%). Independent of the respective sex highest values were observable in Vienna where 407 (2.3%; 240 male 167 female) of 17542 deceased cancer patients received radiation therapy within one month before death. Overall Carinthia ( $n = 79/5932$  1.3%) and Upper Austria ( $n = 168/12804$  1.3%) showed the lowest proportions of patients treated with radiation therapy across Austria.

In Austria 605 persons (0.75% 344 male 261 female) out of all deceased cancer patients ( $n = 80818$ ) have been treated with a monoclonal antibody within 30 days before death. Compared with the Austrian average the proportion of patients who have received a monoclonal antibody before death was nearly twice as high in Salzburg ( $n = 67/4852$  1.4%). In contrast lowest values

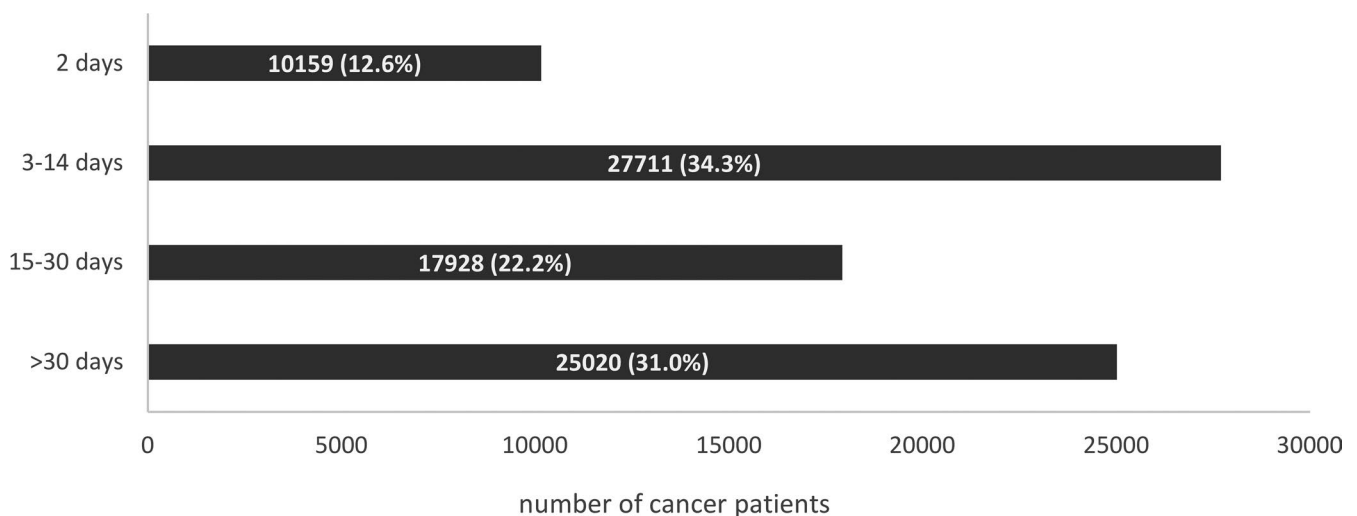


FIGURE 2 Number of days from hospitalisation to death of all deceased cancer patients ( $n = 80818$ )

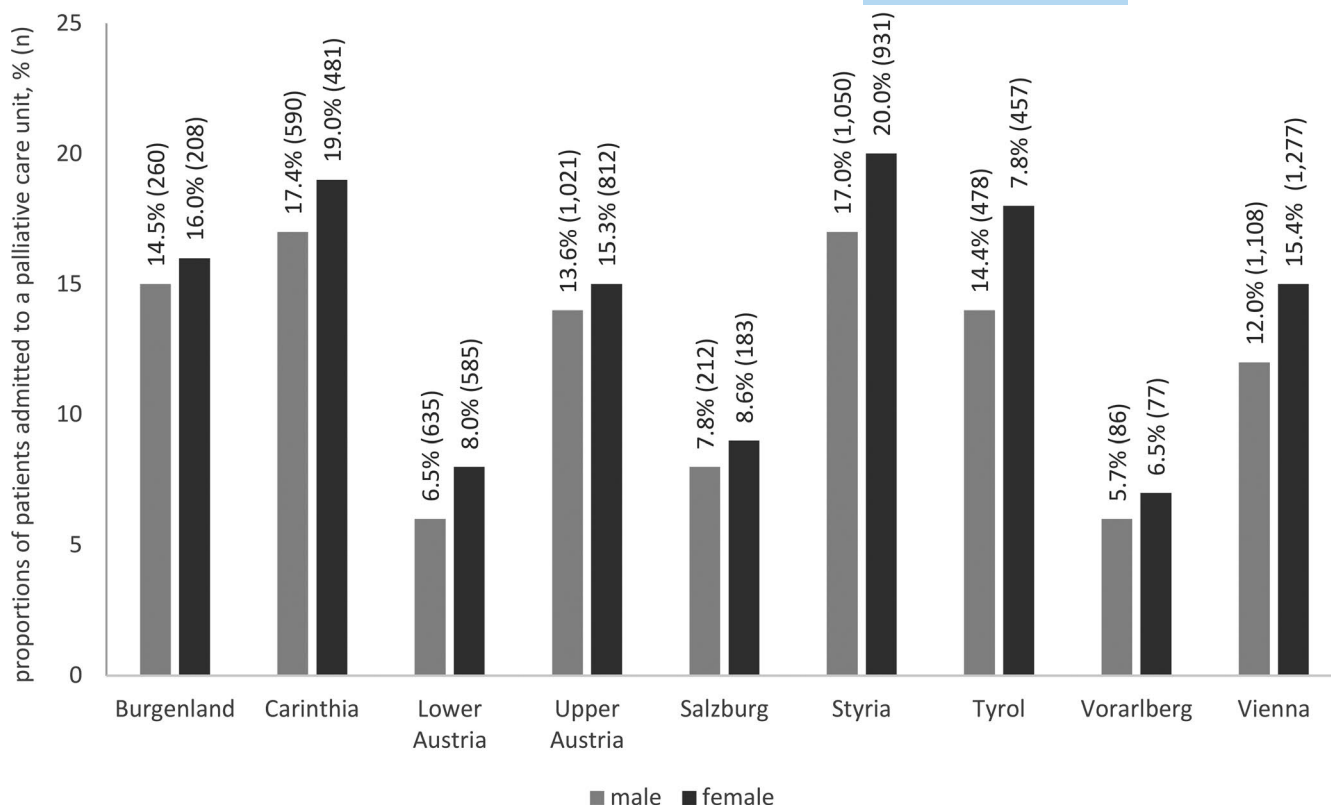


FIGURE 3 Proportion of cancer patients whose last hospital admission before death was to a palliative care unit

were observable in Styria ( $n = 52/10848$  0.5%) and Lower Austria ( $n = 1/17169$  0.5%).

#### 4 | DISCUSSION

Internationally EOL care is considered as an important indicator for the quality of oncological care (Choosing Wisely in cooperation with the American Society of Clinical Oncology (ASCO) 2016; Devos et al. 2019; Nauck 2011; Patera & Wild 2012; Wild & Patera 2011 2013). Hence we aimed to investigate the EOL care of cancer patients across Austria as well as the assessment of potential regional variances between all nine federal states. To evaluate EOL care we were focusing on the place of death the administered therapies closely before death and the palliative hospital care at the EOL.

In Austria 80818 cancer patients have died during our observation period (2012–2016). Out of those 60.8% died in a publicly funded hospital. 10259 (12.6%) of the 80818 deceased cancer patients were admitted to a hospital 2 days before death. Generally the proportion of patients deceased in acute care was homogenous across Austria except for Vienna (75.3%) where the highest values were present. However if persons who potentially died due to an accident were excluded from our analysis the average Austrian proportion of intramural cancer deaths decreases to 53.4%. In the study from Fuchs and Robausch (2018) which was solely focusing on one Austrian region (Lower Austria 19% of Austrian population) the proportion of intramurally deceased

cancer patients was 61.1%. This difference is mainly influenced by the duration of the observation period since our analyses included several (five) years compared with the reference project in which only a single year was considered.

Considering palliative care at the EOL we could see that for 12.9% of the patients the last hospital stay was in a palliative care unit. However it has to be considered that any palliative care services (e.g. palliative care at home etc.) that are offered in the outpatient sector were not part of this research project. This could be one reason for the high regional variability across Austrian federal states and according to variances in the regional availability and access to ambulatory palliative care services. In addition the analysis of specific cancer treatments within 30 days before death showed slight variations across federal states. Thirty days before death 6.9% of the Austrian cancer patients have still received chemotherapy 1.7% radiation therapy and 0.75% were treated with a monoclonal antibody.

Contrasting our data to the results of similar international research the admission rate to a palliative care unit is rather low (12.9%) and happens rather late (23.5% within 2 days before death another 28.3% within 8 to 14 days before death) within Austria compared with Belgium (Devos et al. 2019). However considering the limitation as expressed above of an underestimation of the utilisation of palliative care services in the ambulatory sector in Austria the difference is still high. In Belgium 53% of terminal cancer patients received palliative care in 2015 either at home or in hospitals. Only 18.4% of terminal cancer patients died (2015) within 1 week after the start of palliative care (Devos et al. 2019). An earlier study in Switzerland analysing data from

**TABLE 1** Number of hospitalised patients who have received cancer treatment (chemotherapy radiation therapy and monoclonal antibody) 30 days before death

Cancer treatment	Total	Male	Female
<i>Chemotherapy n (%)</i>			
Total	5580 (6.9)	3327 (7.3)	2253 (6.4)
Burgenland	167 (5.4)	114 (6.4)	53 (4.1)
Carinthia	390 (6.6)	244 (7.2)	146 (5.8)
Lower Austria	1008 (5.9)	629 (6.4)	379 (5.2)
Upper Austria	838 (6.5)	505 (6.7)	333 (6.3)
Salzburg	506 (10.4)	281 (10.3)	225 (10.6)
Styria	633 (5.8)	380 (6.1)	253 (5.4)
Tyrol	458 (7.8)	287 (8.6)	171 (6.7)
Vorarlberg	142 (5.3)	76 (5.1)	66 (5.6)
Vienna	1438 (8.2)	811 (8.8)	627 (7.6)
<i>Radiation therapy n (%)</i>			
Total	1344 (1.7)	833 (1.8)	511 (1.5)
Burgenland	49 (1.6)	36 (2.0)	13 (1.0)
Carinthia	79 (1.3)	48 (1.4)	31 (1.2)
Lower Austria	257 (1.5)	149 (1.5)	108 (1.5)
Upper Austria	168 (1.3)	112 (1.5)	56 (1.1)
Salzburg	78 (1.6)	53 (1.9)	25 (1.2)
Styria	156 (1.4)	99 (1.6)	57 (1.2)
Tyrol	108 (1.8)	68 (2.0)	40 (1.6)
Vorarlberg	42 (1.6)	28 (1.9)	14 (1.2)
Vienna	407 (2.3)	240 (2.6)	167 (2.0)
<i>Monoclonal antibody n (%)</i>			
Total	605 (0.8)	344 (0.8)	261 (0.7)
Burgenland	28 (0.9)	18 (1.0)	10 (0.8)
Carinthia	39 (0.7)	23 (0.7)	16 (0.6)
Lower Austria	89 (0.5)	57 (0.6)	32 (0.4)
Upper Austria	91 (0.7)	50 (0.7)	41 (0.8)
Salzburg	67 (1.4)	33 (1.2)	34 (1.6)
Styria	52 (0.5)	33 (0.5)	19 (0.4)
Tyrol	58 (1.0)	34 (1.0)	24 (0.9)
Vorarlberg	28 (1.0)	15 (1.0)	13 (1.1)
Vienna	153 (0.9)	81 (0.9)	72 (0.9)

2006–2008 found 68.5% palliative care unit patients were hospitalised during the last 30 days before death (Matter-Walstra et al. 2014).

While the difference in the utilisation of palliative care is large an international comparison focusing on cancer patients older than 65 who were dying in hospitals is comparable to our results (Austria: 53.4% excluding accidents) Belgium (51.2%) Canada (52.1%) but lower in the Netherlands with 29.4% or Germany with 38.3% (Bekelman et al. 2016). The hospitalisation rate of patients within 30 days before death is rather high in Austria with 69.0% compared with reference values from Germany the Netherlands England Belgium Canada Norway and the United States that are ranging from

43.2.0% to 62.6% with the lowest values in Germany (44.8%) and the Netherlands (43.2%; Bekelman et al. 2016).

Admission to an ICU within 30 days before death was observed in 8.6% of cancer patients ( $n = 6973/80818$ ) in Austria compared with 11.2% in Belgium and 9.8% in Canada but only 3.8% in Germany and 7% in the Netherlands (Bekelman et al. 2016). However the comparison of reference values is limited by different age groups of the respective study populations. The percentage of patients receiving systemic chemotherapy 30 days before death was rather low (6.9%) in Austria compared with other European countries where it is ranging between 4.8% (Norway) to 22.7% (Italy; Bekelman et al. 2016; De Schreye et al. 2017; Martoni et al. 2007).

There are some limitations to our data analyses: the use of routine data is limited to billing relevant information and ICD diagnose coding more detailed patient-specific data could not be analysed. Thus other relevant quality of care indicators as pain and symptom management or patient-relevant outcomes like quality of life could not be considered. In addition our analyses are mainly limited by the lack of data from the outpatient and ambulatory care sector. This is particularly relevant for the interpretation of the palliative care situation and the regional variances across Austria since in some regions (e.g. in Styria Lower Austria) there are arrangements in place between health insurances and hospitals (hospital corporations) regarding the reimbursement of cancer therapies. Besides the data were source-related and based on the place of residence of the patients identified by cancer diagnoses documented during their inpatient stays. Therefore cross-federal state referrals and potential health care tourism of contiguous federal states may impact the presented analyses. Lastly although the exact date of death was known the cause of death was lacking.

To conclude the available data shows a largely homogeneous picture across the nine federal states of Austria concerning the place of death. The overall rate of patients who died in acute care is comparable to other European countries. There is a certain small variability across the federal states concerning systemic therapies at the EOL. However in international comparison the application of systemic chemotherapy appears rather low. The same accounts for the ICU rate where Austria present moderate values. Considering the quality indicators hospital admission and timely referral to the palliative care setting Austria performs poorly compared with international reference values. Hence even with the limitation of missing data from the outpatient setting the actual utilisation and access to palliative services seems low and far too late as well as the hospitalisation rate is fairly high.

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#### CONFLICT OF INTEREST

None to declare.

## AUTHOR CONTRIBUTIONS

NG and MR conceptualised the manuscript supervised by CW. MR performed all analyses. Two authors conducted the presentation of the data (MR and NG). NG drafted the manuscript in consultation with all authors. The article was critically reviewed and finally approved by all authors.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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