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To cite this article: Sixten Elmstedt, Hanna Mogensen, Dan-Erik Hallmans, Björn Tavelin, Staffan Lundström & Magnus Lindskog (2019) Cancer patients hospitalised in the last week of life risk insufficient care quality – a population-based study from the Swedish Register of Palliative Care, Acta Oncologica, 58:4, 432-438, DOI: [10.1080/0284186X.2018.1556802](https://doi.org/10.1080/0284186X.2018.1556802)

To link to this article: <https://doi.org/10.1080/0284186X.2018.1556802>



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Published online: 11 Jan 2019.



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Cancer patients hospitalised in the last week of life risk insufficient care quality – a population-based study from the Swedish Register of Palliative Care

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ABSTRACT

Background: One-quarter of all cancer deaths in Sweden occur in hospitals. If the place of death affects the quality of end-of-life (EOL) is largely unknown.

Methods: This population-based, retrospective study included all adults cancer deaths reported to the Swedish Register of Palliative Care in 2011–2013 ($N=41,729$). Hospital deaths were compared to deaths occurring in general or specialised palliative care, or in nursing homes with respect to care quality indicators in the last week of life. Odds ratios (OR) with 95% confidence intervals (CI) were calculated with specialised palliative home care as reference.

Results: Preferred place of death was unknown for 63% of hospitalised patients and consistent with the actual place of death in 25% compared to 97% in palliative home care. Hospitalised patients were less likely to be informed when death was imminent (OR: 0.3; CI: 0.28–0.33) as were their families (OR: 0.51; CI: 0.46–0.57). Validated screening tools were less often used in hospitals for assessment of pain (OR: 0.32; CI: 0.30–0.34) or other symptoms (OR: 0.31; CI: 0.28–0.34) despite similar levels of EOL symptoms. Prescriptions of as needed drugs against anxiety (OR: 0.27; CI: 0.24–0.30), nausea (OR: 0.19; CI: 0.17–0.21), or pulmonary secretions (OR: 0.29; CI: 0.26–0.32) were less prevalent in hospitals. Bereavement support was offered after 57% of hospital deaths compared to 87–97% in palliative care units and 72% in nursing homes.

Conclusions: Dying in hospital was associated with inferior end-of-life care quality among cancer patients in Sweden.

ARTICLE HISTORY

Received 18 October 2018
Accepted 30 November 2018

Introduction

Important aspects of end-of-life (EOL) care that emerges when interviewing terminally ill cancer patients include the importance of being free from pain and other distressing symptoms and to be well supported by their health-care team. Clearly, many patients want to be involved in decisions about their EOL phase [1–3]. Studies further indicate that a majority of them wish to be cared for at home in their final days [2,4]. Nevertheless, some patients instead prefer to die in hospice, hospital or a nursing home [5]. In Sweden, one in four cancer patients spends the last week of life in hospital [6]. To what extent a ‘good death’, including adequate symptom control and comfort for the patient as well as information and support to the family, can be equally achieved in a hospital compared to a dedicated palliative care setting is insufficiently studied.

With the ultimate goal of improving the quality of EOL care for all dying people in Sweden, the population-based

national Swedish Register of Palliative Care (SRPC) was launched in 2005. The register collects data through a web-based system from a large number of units and from different care settings based on information extracted from medical records in the last week of life. The collected data mainly reflects the care process, including place of death, information given, offered support, drug prescription and EOL care documentation [7].

Using SRPC data, we undertook the present study to identify or rule out major care quality differences between hospitals and other care settings in Sweden with respect to the EOL care provided to cancer patients in the last week of life.

Methods

The SRPC, which has previously been described [7], registers the majority of all cancer deaths in Sweden (77% in 2011,

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 Supplemental data for this article can be accessed [here](#).

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85% in 2012 and 87% in 2013). The information in the register is based on an EOL questionnaire (Supplementary Table S1). Briefly, the 27-item questionnaire focuses on the quality of care in the last week of life and is answered retrospectively online, most often by the nurse responsible for the EOL care. Only data documented in the patient records are used for registration. Aspects addressed in the questionnaire include information to patient and family, prevalence and severity of symptoms, prescriptions of essential parenteral drugs as needed (PRN), the use of palliative consultation services and bereavement support. Median time from patient death to data entry online is 7 days. The current version is operational since 2012 when it was revised based on a validation study [8].

All adult cancer deaths (≥ 18 years) reported to the SRPC 1 Jan 2011–31 Dec 2013 ($n = 54,213$) were considered for inclusion in the study. After excluding patients with an unexpected or uncertain cause of death ($n = 2937$) as well as those with potentially competing causes of death, i.e., life-threatening comorbidities ($n = 9547$), a study population of expected cancer-related deaths was defined and used for all described analyses, $n = 41,729$.

From the questionnaire, we identified 11 questions mainly associated with different aspects of the care process, listed in Supplementary Table S2. For most quality indicators, a distinctive answer ('yes' or 'no') was registered for more than 90% of patients, corresponding to <10% of patients being excluded from the analysis due to answered as 'do not know' or when missing. For the indicators reflecting information to the patient about care transition (question 11B) and bereavement support (question 18) the proportion of 'do not know' answers were slightly higher, 16% and 17%, respectively. Information on symptom prevalence was based on the answer to question 20 in the questionnaire (Supplementary Table S1).

Linkage with the national Cause of Death Register provided information on the specific type of cancer causing each death (classified according to the International Classification of Disease version 10).

Statistical analyses

For each care quality indicator (dependent variable), we tested if its implementation in the EOL care of a patient (yes/no) was associated with place of death (independent variable). Possible places of death were hospitals, nursing homes (analysed as a composite of short-term and permanent stay), general palliative home care, specialised palliative home care (reference group), or specialised palliative care inpatient units. Logistic regression was used to calculate crude odds ratios (OR) with 95% confidence intervals (CI). IBM SPSS Statistics for Windows, Version 23.0. Armonk, NY: IBM Corp was used for all analyses.

Ethics

The study was approved by the Ethics Committee of the University of Linköping, Dnr 2013/289-31

Role of the funding source

Governmental bodies fund The Swedish Register of Palliative Care. The funders of the study had no role in study design, data collection, data analysis, data interpretation, or writing of the report. All authors had full access to all the data in the study and the corresponding author had final responsibility for the decision to submit for publication.

Results

Study population

The patient characteristics are described in Table 1. 41,729 expected cancer deaths were identified. Of these, 10,348 patients (24.8%) died in hospitals. Fifty percent of all cancer deaths occurred in specialised palliative care. The median length of stay at the place of death was 19 days, shorter in hospitals (9 days) and notably longer in nursing homes with permanent stay. Median age was 74 years. Both genders were equally represented. Table 1 shows the numbers and relative frequencies of patients per diagnosis for the ten most common cancers at the respective place of death.

Place of death: preferences and consistency

The preferred place of death was unknown for 63% of the patients dying in hospitals. In contrast, in palliative home care the patient's wish was unknown in 2% of cases. Consistency between patient preference and actual place of death was lowest for hospital deaths (24.8%). The best consistency (97.3%) was noted for palliative home care deaths (Figure 1).

Transition to EOL care

A decision by the responsible physician to shift to EOL care was documented for 72% of patients in hospitals (OR: 0.75; CI: 0.69–0.81; $p < .001$) compared to 78% in both specialised and general palliative home care, 77% in nursing homes and 80% in specialised palliative inpatient units.

Systematic symptom assessment using validated instruments

Systematic assessment of pain (OR: 0.32; CI: 0.30–0.34, $p < .001$) or other symptoms (OR: 0.31; CI: 0.28–0.34, $p < .001$) using a validated instrument, was less common in hospitals compared to specialised palliative care (Table 2). Patients dying in nursing homes or at home with general palliative care were also unlikely to be assessed with a validated symptom assessment scale.

Symptom prevalence

We next investigated if symptom prevalence, as documented in the medical records and reported to the SRPC, differed according to the place of death, focussing on pain, nausea,

Table 1. Patient characteristics in relation to place of death.

Category	All	Hospital	Nursing home, short term stay	Nursing home, permanent stay	General palliative home care	Specialised palliative home care	Specialised palliative inpatient unit	Other
Number of pts, <i>N</i> (% of all)	41,729 (100)	10,348 (24.8)	4619 (11.1)	3186 (7.6)	2818 (6.8)	7427 (17.8)	13,158 (31.5)	173 (0.4)
Age, y median (range)	74 (18–105)	72 (18–102)	80 (30–99)	85 (26–105)	76.5 (18–104)	71 (18–100)	73 (18–103)	76 (30–97)
Male, %	50	51.5	50	44	55	54	47	50
Female, %	50	48.5	50	56	45	46	53	50
Length of stay, days median (from admission to death)	19	9	19.5	132.5	55	50	11	13.5
Common diagnoses								
Lung cancer [LC], <i>N</i>	6012	1835	617	250	280	924	2086	20
(% of all LC deaths)	(100)	(30.5)	(10.3)	(4.2)	(4.7)	(15.4)	(34.6)	(0.3)
Prostate cancer [PC], <i>N</i>	3741	657	566	439	354	679	1032	14
(% of PC deaths)	(100)	(17.6)	(15.1)	(11.6)	(9.5)	(18.2)	(27.6)	(0.4)
Pancreatic cancer [PancC], <i>N</i>	3462	778	335	138	224	790	1178	19
(% of all PancC deaths)	(100)	(22.5)	(9.7)	(4.0)	(6.5)	(22.8)	(34.0)	(0.5)
Breast cancer [BC], <i>N</i>	2733	607	225	216	155	508	1006	16
(% of all BC deaths)	(100)	(22.2)	(8.2)	(7.9)	(5.7)	(18.6)	(36.8)	(0.6)
Colon cancer [CC], <i>N</i>	2711	539	324	195	246	536	851	20
(% of all CC deaths)	(100)	(19.9)	(11.9)	(7.2)	(9.1)	(19.8)	(31.4)	(0.7)
Rectal cancer [RC], <i>N</i>	1448	261	157	116	132	343	435	4
(% of all RC deaths)	(100)	(18.0)	(10.8)	(8.0)	(9.1)	(23.7)	(30.0)	(0.3)
Ovarian cancer [OC], <i>N</i>	1207	270	116	55	87	240	434	5
(% of all OC deaths)	(100)	(22.4)	(9.6)	(4.6)	(7.2)	(19.9)	(35.9)	(0.4)
Urothelial cancer [UC], <i>N</i>	1126	234	158	92	88	190	361	3
(% of all UC deaths)	(100)	(20.8)	(14.0)	(8.2)	(7.8)	(16.9)	(32.0)	(0.3)
Gastric cancer [GC], <i>N</i>	1069	234	100	58	80	229	363	5
(% of all GC deaths)	(100)	(21.9)	(9.3)	(5.4)	(7.5)	(21.4)	(34.0)	(0.5)
Malignant melanoma [MM], <i>N</i>	1008	215	109	49	67	195	373	0
(% of all MM deaths)	(100)	(21.3)	(10.8)	(4.9)	(6.6)	(19.3)	(37.0)	(0)

anxiety, dyspnoea and pulmonary secretions (Figure 2). Whereas the prevalence of pain (79–85%) and nausea (24–27%) were comparable irrespective of place of death, cancer patients dying in hospitals were more likely to suffer from dyspnoea (OR: 1.99; CI: 1.85–2.15, $p < .001$). Anxiety was more common among inpatients, either in hospitals (OR: 1.50; CI: 1.41–1.61, $p < .001$) or in specialised palliative care inpatient units (OR: 1.45; CI: 1.36–1.53, $p < .001$), without differences between specialised or general palliative home care (OR: 1.07; CI: 0.98–1.17). Pulmonary secretions were slightly more common among inpatients, either in hospitals (OR: 1.25; CI: 1.18–1.33, $p < .001$) or in specialised palliative inpatient units (OR: 1.22; CI: 1.15–1.29, $p = .001$) compared to specialised palliative home care.

Prescriptions of recommended palliative drugs

Table 3 shows PRN prescription patterns at the time of death of four essential types of injectable drugs according to the place of death. Specialised palliative care inpatient units had the highest frequency of relevant PRN prescriptions overall. Most (>90%) of patients had a PRN prescription of an opioid against pain. Hospitalised patients were significantly less likely to have PRN prescriptions against anxiety (OR: 0.27; CI: 0.24–0.30; $p < .001$), nausea (OR: 0.19; CI: 0.17–0.21, $p < .001$) or pulmonary secretions (OR: 0.29; CI: 0.26–0.32, $p < .001$) compared to specialised palliative home care (Table 3).

Information and bereavement support

Ninety percent of the patients ($n = 37,540$) remained conscious and could participate in decision-making until hours or days before their death (Q10 of the EOL questionnaire), enabling analysis of given information about imminent death. Frequencies and ORs are shown in Table 4. Hospitalised cancer patients were less likely to receive information from the physician when death was imminent (OR: 0.30; CI: 0.28–0.33, $p < .001$) compared to cancer patients dying elsewhere. Families were less likely to receive information about imminent death if the patient was hospitalised (OR: 0.51; CI: 0.46–0.57) or in a nursing home as compared to the patient being enrolled in palliative care. Furthermore, families of patients dying in hospitals were the least likely to be offered bereavement support 1–2 months after the death when compared to all other places of death (Table 4).

Discussion

The present population-based nationwide study identifies several disadvantages associated with in-hospital EOL cancer care. The study is based on a unique register for palliative care (SRPC) which includes several indicators of the EOL care process.

When compared to cancer patients dying with support from palliative care teams, hospitalised cancer patients were less likely to have their preference for place of death considered or to be informed when death was imminent. Validated

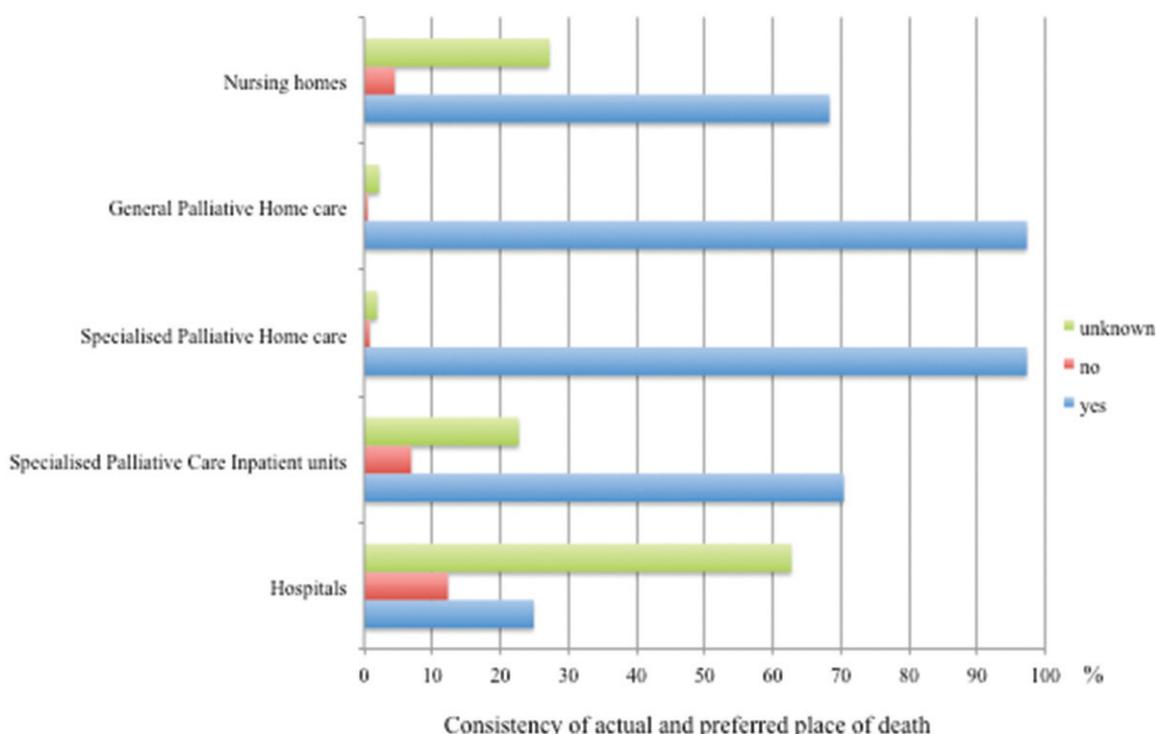


Figure 1. Consistency of preferred and actual place of death. The bars represent percentages of cancer patients for whom the place of death was either in line with ('yes') or inconsistent with ('no') the person's last stated wishes, or whether unknown, as documented in the end-of-life questionnaire (Q12).

Table 2. Use of a validated screening instrument to assess end-of-life symptoms among cancer patients.

Symptom assessed (validated instrument*)	Hospitals		Spec Palliative Inpatient units		Spec Palliative Home care		Gen Palliative Home care		Nursing homes	
	%	OR (95% CI)	%	OR (95% CI)	%	OR	%	OR (95% CI)	%	OR (95% CI)
Pain	22.9	0.32 (0.30–0.34)	43.0	0.81 (0.77–0.86)	48.2	ref	27.8	0.41 (0.38–0.46)	24.2	0.34 (0.32–0.37)
Other symptoms	9.9	0.31 (0.28–0.34)	24.4	0.91 (0.85–0.97)	26.1	ref	13.0	0.42 (0.37–0.48)	12.2	0.39 (0.36–0.43)

*VAS: NRS or another validated symptom assessment scale. OR: Odds ratio. ORs and *p* values were calculated using specialised palliative home care as reference (ref).

symptom screening instruments were less often used and preparedness to relieve distressing symptoms other than pain in the death was insufficient in hospitals. Furthermore, bereavement support was infrequently offered to the family after a hospital cancer death. Hence, our findings, although indirect by means of a proxy questionnaire, substantiate previous reports of poorer quality of care when cancer patients die in hospitals [9–12].

Symptoms may develop rapidly in the last phase of life. Therefore, international experts have agreed on what drugs should be considered essential in EOL [13]. We found three out of four essential drugs to be under-prescribed for PRN injection use among dying hospitalised cancer patients; these were antiemetics, sedatives and antimuscarinics. Differences were pronounced and could not be motivated by differences in symptom prevalence during the last week of life. While the prevalence of pain and nausea was comparable irrespective of place of death, anxiety and in particular dyspnoea was more common in hospitals and in palliative inpatient units. This likely indicates that more symptomatic patients are referred to inpatient care in the EOL phase, and may not represent a difference in the management of

dyspnoea in the different care settings (referral bias). A previous study reported pronounced differences in the use of opioids, midazolam, haloperidol and drugs against pulmonary secretion between hospitals and palliative care inpatient units in the final three days of life [14]. Our population-based data from more than 40,000 cancer patients substantiate these earlier findings and highlight systematic differences in PRN prescriptions between specialised palliative care and hospitals. Notably, information was only available with respect to prescriptions and not actual use of these drugs. A clear gap in the use of validated instruments for symptom assessment was seen between specialised palliative care on one hand and hospitals, nursing homes and general home palliative care on the other. These observations underline the need for continuous education of non-palliative care specialists in EOL symptom management.

For some cancer patients and their families, the hospital ward may provide a sense of security and medical competence [15]. A desire to be discharged to die at home may not come until death is imminent, leaving little time for nurses and physicians to complete the multiple tasks necessary in order for the transfer to be realised [16]. This

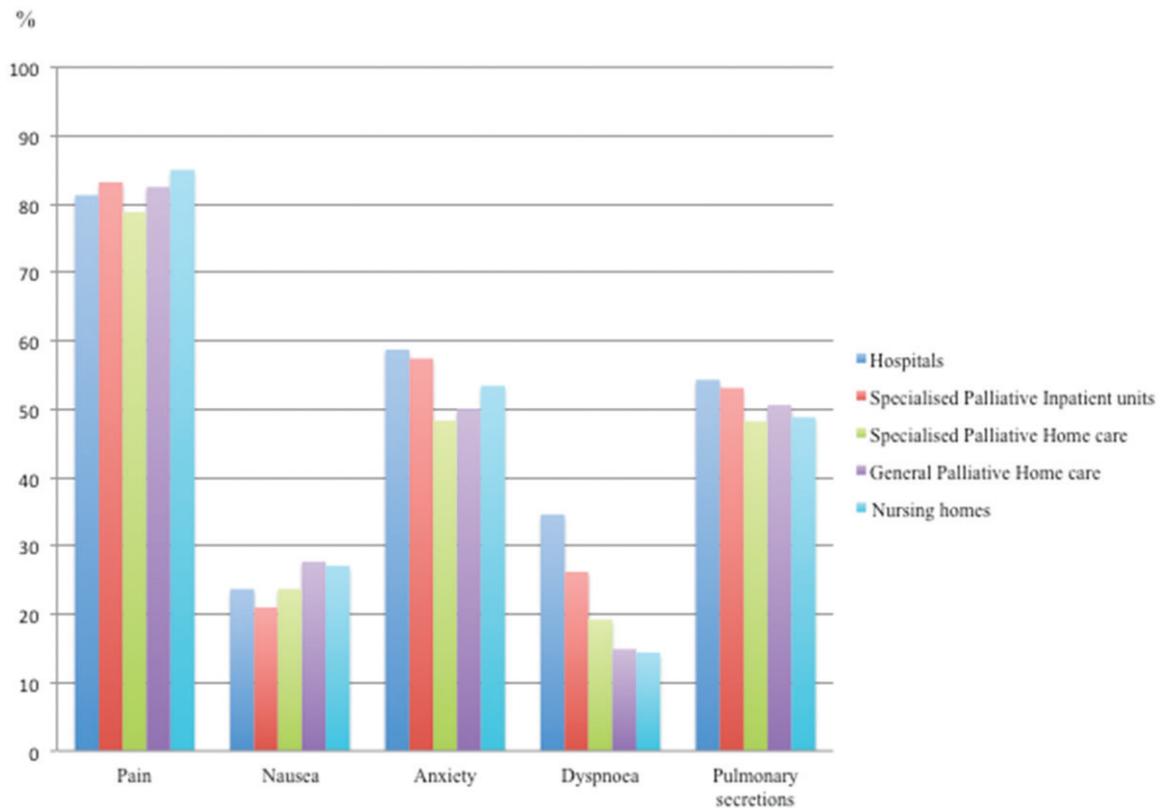


Figure 2. Symptom prevalence in relation to place of death in the last week of life. The bars represent percentages of cancer patients reporting a specific symptom at any time point in the last week of life as documented in the end-of-life questionnaire (Q20).

Table 3. PRN prescriptions at the time of death of symptom-relieving drugs for parenteral use.

Category	Hospitals		Spec Palliative Inpatient units		Spec Palliative Home care		Gen Palliative Home care		Nursing homes	
	%	OR (95% CI)	%	OR (95% CI)	%	OR	%	OR (95% CI)	%	OR (95% CI)
Analgesic	94.7	0.55 (0.47–0.65)	99.1	3.60 (2.9–4.5)	97.0	ref	96.2	0.79 (0.62–1.0)	96.6	0.89 (0.74–1.1)
Sedative	83.1	0.27 (0.24–0.30)	97.8	2.45 (2.1–2.9)	94.8	ref	91.2	0.57 (0.48–0.67)	89.1	0.45 (0.40–0.51)
Antiemetic	63.9	0.19 (0.17–0.21)	94.4	1.78 (1.60–1.98)	90.4	ref	80.2	0.43 (0.38–0.49)	76.7	0.35 (0.32–0.38)
Antimuscarinic	78.6	0.29 (0.26–0.32)	96.2	2.0 (1.8–2.3)	92.7	ref	90.7	0.77 (0.66–0.90)	89.7	0.69 (0.61–0.77)

Percentage of cancer patients, who, at their time of death, had in their medical records a prescription of an injectable drug against pain (analgesic), anxiety (sedative), nausea (antiemetic), or pulmonary secretions (antimuscarinic) to be used as needed (PRN). OR: Odds ratio. ORs and *p* values were calculated using specialised palliative home care as reference. Spec: specialised; Gen: General.

Table 4. Information and bereavement support.

Category	Hospitals		Spec Palliative Inpatient units		Spec Palliative Home care		Gen Palliative Home care		Nursing homes	
	%	OR (95% CI)	%	OR (95% CI)	%	OR	%	OR (95% CI)	%	OR (95% CI)
Patient informed about ImD	69.6	0.30 (0.28–0.33)	86.6	0.85 (0.78–0.94)	88.4	ref	91.4	1.40 (1.19–1.65)	81.7	0.59 (0.53–0.65)
Family informed about ImD	86.7	0.51 (0.46–0.57)	93.7	1.18 (1.06–1.33)	92.7	ref	91.0	0.80 (0.68–0.95)	86.2	0.50 (0.44–0.56)
Bereavement Support offered	57.1	0.04 (0.03–0.05)	94.2	0.44 (0.37–0.52)	97.4	ref	87.0	0.19 (0.15–0.22)	71.7	0.07 (0.06–0.08)

Top two rows show, for each place of death category, the percentage of patients and their families (defined as close friend(s)/relative(s)), respectively, who had an individually tailored and informed conversation with a physician, that was documented in the medical records, about the transition to EOL care when death was imminent. All patients died an expected death. The bottom row shows to what extent the patients' families (close friend(s)/relative(s)) were offered a follow-up talk (bereavement support) within 1–2 months of the death. OR: odds ratio. ORs and *p* values were calculated using specialised palliative home care as reference. ImD: imminent death.

emphasises the necessity to openly inform patients and families when death is imminent as this improves the EOL care [17]. In our study, physicians and nurses failed to do so in one-third of cancer patients dying in hospitals. A half-day course directed to physicians and nurses was found to increase the proportion of patients who received information about the transition to EOL care in the hospital or

nursing home setting [18]. Notably, for patients remaining in a hospital bed as death approaches, even simple measures can increase the likelihood of a better quality of dying, e.g. having a single room, active communication with patients and relatives, providing nurses with training in EOL care and utilising palliative care consultation services [19,20].

Involving the patient in the care process is at least as important in the EOL phase as earlier in the disease. We found the patient's own preference of place of death to be reported as 'unknown' for almost two-thirds of hospital deaths. It is unclear whether this is due to unwillingness or unpreparedness among staff to discuss this issue or due to poor documentation in hospital medical records of discussions that did, in fact, take place.

A shorter duration of stay, from admission to death, in hospitals compared to other places of death could have influenced the outcome in our study by making hospital deaths more difficult to anticipate and prepare for. However, to adjust for this possible difference we included only deaths reported to the SRPC as 'expected based on the disease trajectory' in our analyses. Hence, we believe that we have minimised the differences in preparedness for the death among care staff, when comparing hospital wards with other places of death.

Our study identified several weaknesses in the EOL care process in hospitals where improvements are necessary. We speculate that insufficient training in palliative medicine, together with an overload of patients and lack of beds and staff, typical of acute hospitals in Sweden, might explain the problems observed around management of EOL cancer care. Also, a majority of Swedish acute hospitals lack palliative care consultation services. This deficiency is noteworthy when comparing hospital EOL care quality with other western countries and might in part explain deficiencies found in our study. A recent study indicates that many physicians believe regular caregivers to be sufficiently skilled in palliative care [21]. Our study suggests that this may not be the case, at least in a Swedish setting. An on-going investigation into the reasons for EOL hospitalisation and further analyses of the flows of terminal patients between different care environments is currently being pursued as a collaborative study in Sweden.

In addition to the inclusion of a large number of patients, the strengths of this study further include the high coverage of the SRPC regarding cancer deaths in Sweden, limiting selection bias which might be problematic in studies in this area relying on participation. Moreover, the items of the EOL questionnaire that we used as indicators of the care process were chosen in accordance with international recommendations [22,23]. However, our study also has several limitations: The study design only permits associations and preclude conclusions on cause-and-effect. The SRPC specifically addresses the care provided during the last week of life and the findings should not be extrapolated to palliative cancer care in general. For patients admitted less than one week prior to the death it is likely that the information in the SRPC refers only to the period of terminal care at the place of death due to different systems for medical records between caregivers. However, even if based on a shorter time period, the quality indicators correspond to the EOL care and were therefore also considered. Nevertheless, pitfalls may exist: i.e. there could be a higher proportion of 'do not know' answers among patients admitted close to death and we cannot rule out that an unknown proportion of such patients and their

families had e.g. already been informed about the imminent death, offered support or screened for symptom severity prior to admission to the final place of death. Moreover, nineteen per cent of all cancer deaths in Sweden during the study period were not reported to the SRPC. We cannot know if the association between place of death and quality of EOL care in that group differs from the association found in this study, but we consider any substantial differences unlikely due to the consistency of our findings. Even though the data reported to the SRPC is based on documentation in medical charts, validity is not absolute, in particular regarding symptom prevalence [8], and recall bias among reporting staff may have introduced errors. For example, there is a possibility of recall bias when retrospectively reporting a death as 'expected' or not. This may have led to a certain degree of misclassification of truly unexpected deaths as 'expected'. Potentially, this misclassification is more common in hospitals, and if so, the quality indicators could appear worse than they really were in comparison to other care settings. We chose not to adjust for any covariates in the regression models and instead present crude associations between place of death and EOL care indicators. We believe these convey an important message and correspond to the aim of this study of examining the existence of differences in EOL care quality between hospitals and other care settings, irrespective of underlying reasons for such. We consider other factors potentially influencing the associations as explanations rather than confounders, and these should be investigated in depth in future studies of underlying mechanisms.

Multiple and complex reasons likely contribute to hospital admissions in EOL [24,25] and our data did not permit investigations into the cause for hospitalisation. One possible reason not to discharge a dying patient from the hospital might be an overwhelming burden of symptoms. Similarly, patients cared for at home may require admittance to hospital in the last phase of life due to the progression of distressing symptoms. Hence, importantly, referral bias needs to be considered when interpreting our data. Further research efforts to identify potential preventive measures to avoid hospitalisation in the terminal phase should be encouraged. For example, data support the idea of early referral to palliative care as one strategy [26–28]. Not postponing discussions about EOL care may prevent some hospital admissions of terminally ill patients [29].

In conclusion, using a population-based nationwide approach, we have detected systematic differences in EOL care quality among Swedish cancer patients in their last week of life in relation to place of death. In particular, our findings stress a need for improvement of the palliative care process for hospitalised patients in the terminal phase. Further research is needed to identify what underlying mechanisms contribute to these differences as well as to identify strategies to ensure equality and competence in EOL care irrespective of place of death.

Disclosure statement

No potential conflict of interest was reported by the authors.

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