



# Old age as risk indicator for poor end-of-life care quality – A population-based study of cancer deaths from the Swedish Register of Palliative Care



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## KEYWORDS

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**Abstract Background:** If patient age affects the quality of end-of-life care in cancer is unknown. Using data from a population-based register of palliative care in Sweden, we addressed this question.

**Methods:** This nation-wide study focused on the last week of life of adults dying from cancer in 2011–2012, based on data reported to a national quality register for end-of-life care ( $N = 26,976$ ). We specifically investigated if age-dependent differences were present with respect to thirteen indicators of palliative care quality. Patients were categorised in one out of five pre-defined age groups. Odds ratios (OR) with 95% confidence intervals (CIs), adjusted for type of end-of-life care unit, were calculated using logistic regression, with the oldest group as reference.

**Findings:** Age-dependent differences in implementation rate were detected for ten out of thirteen end-of-life care quality indicators, most of which were progressively less well met with each increment in age group. Compared to elderly cancer patients, young patients were more often informed about imminent death, (OR, 3.9; 95% CI 2.5–5.9,  $p < 0.001$ ), were more often systematically assessed for the presence and severity of pain (OR, 1.6; 95% CI 1.2–2.1,  $p < 0.001$ ) or other symptoms (OR, 1.4; 95% CI 1.0–1.9,  $p = 0.044$ ), were more likely to be assessed by palliative care consultation services (OR, 4.3; 95% CI 3.3–5.7,  $p < 0.001$ ) and to have injections prescribed as needed against pain (OR, 3.4; 95% CI 1.3–9.4,  $p = 0.016$ ), anxiety (OR, 3.8; 95% CI 2.0–7.1,  $p < 0.001$ ) or nausea (OR, 3.6; 95% CI 2.3–5.7,  $p < 0.001$ ). The

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families of young patients were more likely to be informed about imminent death (OR, 2.6; 95% CI 1.5–4.3,  $p = 0.001$ ) and to be offered bereavement support (OR, 4.6; 95% CI 2.7–7.8,  $p < 0.001$ ).

**Interpretation:** Old age is a risk indicator for poor end-of-life care quality among cancer patients in Sweden.

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## 1. Introduction

Fatal cancers affect all age groups, in contrast to many other common causes of non-accidental death. Among disease-related causes of premature death in young adults in Europe, cancer is the most important, contributing to one third of all standard expected years of life lost among both women and men [1]. Analysing age groups among younger individuals, cancer holds a dominating position as a leading cause of non-accidental death among individuals in their 20s, 30s, 40s and 50s [2]. Palliative care of young patients with advanced cancer is more aggressive than that of elderly patients, typically involving the continuation of antineoplastic treatments and hospital care in the last months or weeks of life, which may have a substantial impact on end-of-life (EOL) care [3–6]. Meanwhile, the majority of citizens live increasingly longer, leading to larger proportions of elderly patients with cancer in need of palliative care [7]. Several studies show elderly cancer patients to be less likely enrolled in palliative care programs or referred later, to more seldom die at home or in hospice, and to receive fewer nursing visits or physician house calls in the end of their lives compared to younger patients [8–12]. Nation-wide or cross-national data are scarce and previous studies found complex associations of age and palliative care enrolment [13–15].

The Swedish health care system and its organisation of palliative care have been described previously [16]. Since its introduction in 2005 the Swedish Register of Palliative Care (SRPC), a nation-wide quality register of end-of-life care, has continued to expand and now gathers data from two thirds of all deaths, covering all counties and municipalities in Sweden. It thus enables health care providers, authorities and clinical researchers to retrospectively assess important aspects of EOL care in a standardised way and in different care settings, with the data available online [16]. The SRPC registered 90% of all cancer deaths during 2014 and registration in SRPC has become one of the national quality indicators for cancer care in Sweden.

In this study, we took advantage of the SRPC to investigate if age-related differences exist in the quality of end-of-life care of dying cancer patients in Sweden.

## 2. Methods

### 2.1. Study population

We extracted registry data for all reported adult cancer deaths from 1st January 2011, until 31st December 2012, with exclusion criteria being unexpected death, other competing causes of death, or age below 18 at the time of death. The study population ( $N = 26,976$ ) was then categorised in five pre-defined age-categories: 18–39 years (group 1,  $n = 341$ ), 40–59 years (group 2,  $n = 3017$ ), 60–74 years (group 3,  $n = 10,126$ ), 75–84 years (group 4,  $n = 8393$ ) and  $\geq 85$  years (group 5,  $n = 5099$ ).

### 2.2. End-of-life questionnaire

The questionnaire focuses on the quality of care in the last week of life and is answered retrospectively online as soon as possible after the patient's death by the nurse and/or the physician responsible for the EOL care. If the patient has moved between different caring units during the last week of life, the staff on the unit where the death occurred completes the questionnaire. Median time from patient death to data entry online is 7 days. Only data documented in the patient records are considered. Based on a validation study comparing patient data reported to the quality register with the information documented in actual patient records, the questionnaire was revised and the current version has been in use since January 2011 encompassing deaths from the entire year of 2011 and onwards [17]. The questionnaire consists of 27 questions about e.g. information to patient and family, bereavement support, systematic symptom assessment and symptom severity, prescriptions of essential drugs as needed (PRN), parenteral fluid therapy (FT) and the use of palliative consultation services (Supplementary Table S1). The registration is partly self instructive and, when considered needed, explanations are available on the registration web page. All reporting care units provide the SRPC with an annual update on basic facts about the care unit, availability of staff, existing documented routines around end-of-life care and accessibility to injectable drugs for PRN use to control symptoms. The discipline answering the questionnaire is registered for every single questionnaire with 91% of

the registrants being nurses. In specialised palliative care the proportion of registrations made by physicians is higher (26%) compared to hospitals (7%) and nursing homes (1%).

From the questionnaire, we identified 13 questions associated with different aspects of care quality, listed in [Supplementary Table S2](#) [16]. Items addressed included decision-making, patient participation, information, bereavement support, general quality of care, symptom screening and symptom control. Only patients who had remained conscious until hours or days before their death were included in the analyses of answers related to information about imminent death. All included patients were reported to have died an expected death.

For each of the 13 quality indicators, the data analysis was based on those patients for whom the implementation of that specific indicator in the EOL care was known, i.e. answered by 'yes' or 'no'. For most quality indicators, a distinctive answer was registered for more than 90% of patients in all age groups, corresponding to <10% of patients being excluded from the analysis (drop-outs). For the indicators reflecting information to the patient about care transition (question 11B, [Table S1](#)), bereavement support (question 18, [Table S1](#)) and, actual in relation to preferred place of death (question 12, [Table S1](#)) the proportion of 'do not know' answers were 16%, 17% and 35%, respectively.

### 2.3. Statistics

For each care quality indicator, we tested whether or not its implementation in the end-of-life care of a patient could be predicted by the patient's age (independent variable), using pre-defined age categories. For each patient, a specific quality indicator could be either implemented or not implemented in the care. The association was analysed by logistic regression, adjusting for type of care unit in order to control for potential confounding. Using the oldest age category as reference, we calculated odds ratios (OR) with 95% confidence intervals to describe the likelihood that a specific care quality indicator would be implemented in the end-of-life care in each respective age category.

### 2.4. Ethics

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

### 2.5. Role of the funding source

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.

## 3. Results

### 3.1. Study population

4446 care units registered patient data in the SRPC in 2011–2012. The coverage of cancer deaths in Sweden by SRPC during these two years was 77% and 85% respectively, corresponding to 26, 976 deaths. Patient characteristics are described in [Table 1](#). Both genders were equally represented. Comparison of SRPC data with information from the national cause of death register allowed separation of major cancer diagnoses. Lung, colorectal, prostate, breast and pancreatic cancers were the most common specific diagnoses. For a substantial part of the patient population, as identified in the SRPC to have died of cancer without competing causes of death, the type of underlying malignancy was not specified in the national cause of death register. Fifty percent of the deaths occurred in specialised palliative care (in-patient units and home care).

### 3.2. General characteristics of end-of-life care

The major types of care units delivering EOL care to Swedish cancer patients were hospitals, nursing homes, general or specialised palliative home care and specialised palliative care in-patient units ([Table 1](#)). [Fig. 1](#) shows the age-related trends with respect to place of death among cancer patients reported to the SRPC. Young patients more often died in specialised palliative care. The oldest patients more commonly died in nursing homes. 59% of all patients died at their preferred place without differences between age groups. The presence of a family member or a caregiver at the time of the death was inversely associated with age, with dying alone being four-fold more likely in the oldest group of patients compared to the youngest ([Table 2](#)).

### 3.3. Information and bereavement support

[Table 3](#) shows the propensity to inform patients and their families, respectively, about imminent death, as well as offering bereavement support, in relation to patient age. Elderly patients were less often informed when death was imminent compared to younger patients, so were the families of elderly patients compared to families of younger patients. Moreover, families of younger patients were more likely to be offered bereavement support 1–2 months after the death.

### 3.4. Medical decision-making and preparedness for end-of-life care

A medical decision to focus only on EOL care was present in the patient records of 63% of the patients (range 60–67) without age-related differences. Younger patients more often had an anxiolytic drug prescribed

Table 1  
Characteristics of cancer patients reported to the SRPC.

Category	Number (n)	%
All patients	26,976	100
Age (y)		
Mean, y (range)	73.3 (18–105)	100
18–39	341	1.3
40–59	3017	11.2
60–74	10,126	37.5
75–84	8393	31.1
≥85	5099	18.9
Sex		
Female	13,376	49.6
Male	13,600	50.4
EOL care		
Hospital	6536	24.2
Nursing home	5076	18.8
Short-term stay	2994	11.1
Permanent stay	2082	7.7
General home PC	1776	6.6
Specialised home PC	4916	18.2
Specialised in-patient PC	8547	31.7
Other	125	0.5
Cause of death <sup>#</sup>		
Lung	3907	14.5
Breast	1735	6.4
Prostate	2486	9.2
Colorectal	3121	11.6
Pancreatic	2255	8.4
Upper GI	1365	5.1
Haematological	1594	5.9
Gynaecological	1151	4.3
Bladder	706	2.6
Melanoma	661	2.5
Renal	627	2.3
CNS primary	624	2.3
CUP	545	2
Head-Neck	242	0.9
Other	5957	22.1

Data describing the end-of-life care during the last week of life of patients who died an expected death from cancer from 1st January 2011 to 31st December 2012. SRPC = The Swedish Register of Palliative Care. EOL = end-of-life. PC = palliative care. GI = gastrointestinal. CUP = metastatic cancer of unknown primary tumour.

<sup>#</sup> Underlying type of malignancy, according to the national cause of death register in Sweden for 2011–2012.

PRN compared with elderly patients. A similar age-related prescription pattern was observed for antiemetics (Table 4). A large majority of patients were prescribed PRN injections against pain, with numerically small differences between age groups. No meaningful differences were detected between age groups with reference to PRN prescriptions against death rattles (anticholinergic drugs).

### 3.5. Systematic assessment of end-of-life symptoms

Systematic assessment for the presence and severity of pain (by means of NRS, VAS or another validated

instrument) was more often done in younger patients. As for systematic assessment of symptoms other than pain, a small but significantly higher frequency was noted for the youngest patients (group 1) whereas groups 2–5 did not differ significantly from each other (Table 5).

### 3.6. Palliative care consultations

The EOL questionnaire provides information about the use of palliative care consultation services in the last week of life, including assessment of the patient by a pain specialist, or by members of a specialised palliative care team. The likelihood for patients to receive expert support from palliative care consultation services decreased with increasing age, and the difference remained after adjustment for type of care unit (Table 6).

## 4. Discussion

This nation-wide population-based study identifies for the first time the existence and magnitude of age-related differences in the quality of end-of-life care during the last week of life for cancer patients. We found ten out of thirteen analysed proxies for quality of care to be significantly associated with patient age. These indicators reflect typical core aspects of palliative care e.g. information to the patients and their families as death is imminent, systematic assessment of pain and other symptoms, the prescription of essential drugs for symptom control as needed and whether or not bereavement support had been offered. The implementation rate for most of them tapered with each increment in age. The inevitable conclusion of our findings is that increasing age is a risk indicator for sub-optimal palliative care during the last week of life among cancer patients in Sweden. This is novel information and of considerable relevance to the international palliative care community, which to a large extent cares for an ageing population of dying cancer patients [7].

Information to the patient and the family upon shifting the focus of care from an early palliative phase, which often includes attempts to control the disease, to end-of-life care, is considered a cornerstone of palliative care. Lundquist and colleagues showed that the overall quality of the EOL care is higher among cancer patients who have been informed about their imminent death [18]. We found that elderly cancer patients were less likely to be informed by their responsible physician when death was imminent. In addition, families of elderly cancer patients were disadvantaged in terms of less likely being informed about the patient's imminent death or offered bereavement support. It is possible that this reflects an attitude of a cancer-related death as being less traumatic if the individual is of old age. However,

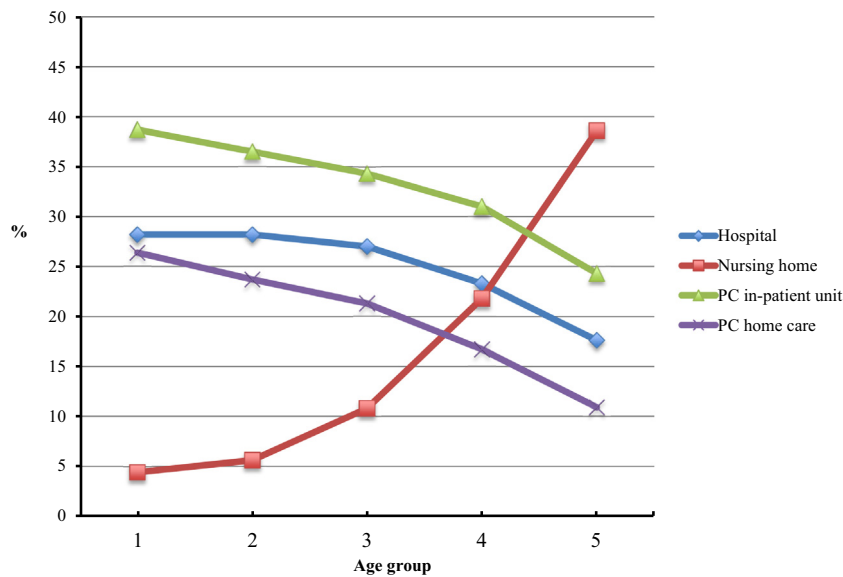


Fig. 1. Type of end-of-life care unit in relation to patient age.

Table 2

The likelihood of dying in the presence of a family member or care giver.

Group	Age (y)	%	Odds ratios (OR)	95% confidence interval (CI)	<i>p</i>
1	18–39	96.3	6.0	3.2–11.0	<0.001
2	40–59	92.1	2.8	2.2–3.2	<0.001
3	60–74	89.4	1.9	1.7–2.1	<0.001
4	75–84	85.1	1.2	1.1–1.4	<0.001
5	≥85	83.1	1		

Proportions of cancer patients in each age category who died in the presence of a family member or a care giver, i.e. did not die alone, according to the Swedish Register of Palliative Care, during the study period 1st January 2011 to 31st December 2012. OR = Odds ratio adjusted for type of end-of-life care unit. ORs and *p*-values were calculated using Group 5 as reference.

we detected a gradient across the whole age span indicating that, more likely, the older the patient, the less attention is given to information issues.

Fifty percent of the Swedish cancer patients are not enrolled in specialised palliative care at the time of death. For this group of patients, of whom many are elderly, the access to palliative care consultation services e.g. pain specialists and palliative care teams is of paramount importance. Adjusting for type of care unit, we found that such consultation services were less frequently involved in the care of elderly cancer patients as compared to younger cancer patients. This contrast to the findings by Olden and colleagues, however, their study population was not restricted to patients receiving end-of-life care [19]. Our results indicate that Swedish elderly cancer patients are disadvantaged in terms of poorer access to palliative care expertise and thus likely have an increased risk of suffering in the event of rapidly developing symptoms, compared to younger cancer patients. Furthermore, elderly patients dying from cancer were less often assessed systematically for the presence and severity of pain, and were less often prescribed essential drugs to control symptoms as needed, compared to younger patients. Analysing charts

of individuals who died in nursing homes, Reynolds and colleagues found no age-related difference in the presence of pain. However, they noted that nurses more often described the pain of elderly residents as ‘mild’ compared to younger residents [20]. A retrospective review of inpatient palliative care consultations to patients with various diagnoses found that, patients older than 85 were less likely to report pain, anxiety and nausea but more likely to report anorexia than younger patients [19]. In contrast, Bennet et al reported older and younger cancer patients living at home to have similar experiences of pain [21]. Importantly, symptoms may develop rapidly and patients can deteriorate suddenly in EOL care. Therefore, in the absence of solid, unequivocal proof, any beliefs regarding age-dependent differences in symptom prevalence or severity should be disregarded when medical decisions are made in palliative care.

We found lung, colorectal, prostate, pancreatic and breast cancers to be the most common specific causes of cancer-related death among our cases in this study. From a disease profile perspective, this corresponds well to data reported by the National Board of Health and Welfare in Sweden as well as from the Swedish Cancer

Table 3  
Information and bereavement support in relation to patient age.

Group	Age (y)	Patient informed				Family informed				Bereavement support			
		%	Odds ratios (OR)	95% confidence interval (CI)	<i>p</i>	%	OR	95% CI	<i>p</i>	%	OR	95% CI	<i>p</i>
1	18–39	90.8	3.9	2.5–5.9	<0.001	94.8	2.6	1.5–4.3	0.001	93.5	4.6	2.7–7.8	<0.001
2	40–59	85.7	2.2	1.9–2.6	<0.001	93.0	1.9	1.5–2.3	<0.001	88.3	2.3	2.0–2.8	<0.001
3	60–74	82.5	1.7	1.6–1.9	<0.001	90.5	1.4	1.2–1.6	<0.001	85.1	1.7	1.5–1.9	<0.001
4	75–84	79.5	1.4	1.3–1.6	<0.001	89.1	1.2	1.1–1.4	0.001	80.8	1.3	1.2–1.5	<0.001
5	≥85	73.8	1			85.8	1			74.4	1		

Data in the far left and middle panels show, for each patient age category, the proportion 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 end-of-life care. All patients died an expected death. The panel to the far right shows to what extent the patients' families (close friend(s)/relative(s)) were offered a follow-up talk within 1–2 months of the death. OR = odds ratio adjusted for type of end-of-life care unit. ORs and *p*-values were calculated using Group 5 as reference.

Table 4  
End-of-life prescriptions of injectable drugs for symptom relief.

Group	Age (y)	Analgesic				Antiemetic				Anxiolytic				Anticholinergic			
		%	Odds ratios (OR)	95% confidence interval (CI)	<i>p</i>	%	OR	95% CI	<i>p</i>	%	OR	95% CI	<i>p</i>	%	OR	95% CI	<i>p</i>
1	18–39	98.7	3.4	1.3–9.4	0.016	91.8	3.6	2.3–5.7	<0.001	96.3	3.8	2.0–7.1	<0.001	89.6	1.3	0.9–1.9	0.21
2	40–59	97.9	2.2	1.6–3.0	<0.001	86.7	2.0	1.8–2.4	<0.001	94.9	2.7	2.2–3.3	<0.001	89.6	1.3	1.1–1.5	0.003
3	60–74	97.2	1.6	1.3–2.0	<0.001	82.6	1.5	1.3–1.6	<0.001	92.0	1.7	1.5–1.9	<0.001	88.8	1.2	1.1–1.4	0.007
4	75–84	96.8	1.4	1.1–1.7	0.002	79.8	1.2	1.1–1.4	<0.001	89.7	1.3	1.1–1.4	0.001	88.7	1.2	1.0–1.3	0.024
5	≥85	95.6	1			75.7	1			87.1	1			87.4	1		

The proportion of patients, in each age category, who, at their time of death, had in their medical records a prescription of an injectable drug against pain (analgesic), nausea (antiemetic), anxiety (anxiolytic) or death rattles (anticholinergic) to be used as needed. OR = Odds ratio adjusted for type of end-of-life care unit. ORs and *p*-values were calculated using Group 5 as reference.

Table 5  
Systematic assessment of pain or other symptoms.

Group	Age (y)	Pain assessed <sup>#</sup>				Other symptoms assessed <sup>#</sup>			
		%	Odds ratios (OR)	95% confidence interval (CI)	<i>p</i>	%	OR	95% CI	<i>p</i>
1	18–39	42.0	1.6	1.2–2.1	<0.001	24.1	1.4	1.0–1.9	0.044
2	40–59	39.3	1.5	1.3–1.6	<0.001	19.9	1.1	1.0–1.3	0.18
3	60–74	37.0	1.4	1.3–1.5	<0.001	19.2	1.1	1.0–1.2	0.12
4	75–84	30.0	1.1	1.0–1.2	0.15	15.8	0.9	0.8–1.0	0.18
5	≥85	26.2	1			15.5	1		

OR = odds ratio adjusted for type of end-of-life care unit.

Group 5 was used as reference to calculate ORs and *p*-values.

<sup>#</sup> Assessed systematically by validated scale.

Table 6  
Use of palliative consultation services in end-of-life care.

Group	Age (y)	%	Odds ratios (OR)	95% confidence interval (CI)	<i>p</i>
1	18–39	34.9	4.3	3.3–5.7	<0.001
2	40–59	28.0	2.9	2.5–3.3	<0.001
3	60–74	24.5	2.1	1.9–2.3	<0.001
4	75–84	21.5	1.4	1.2–1.5	<0.001
5	≥85	19.7	1		

OR = odds ratio adjusted for type of end-of-life care unit. ORs and *p*-values were calculated using Group 5 as reference.

Foundation. Also, the age distribution of our cases was similar to what can be found in national databases on cancer statistics in Sweden.

As expected, elderly patients were more likely to die in nursing homes, whereas younger patients were more commonly admitted to specialised palliative care in-patient units or home care units. To correct for any discrepancies in adherence to palliative care quality guidelines, all odds ratios presented in this study were calculated adjusting for type of care unit.

Our study has limitations. The indicators of care quality that we used mostly addressed care processes and to some extent outcomes (dying at the preferred place), based on documentation in the medical records [22]. This focus is consistent with most previous work on quality estimates in palliative care, as discussed by De Roo and colleagues in their systematic review [23]. An important consequence hereof is that, we lack insight into the patients' own experiences of the end-of-life care provided in the respective age groups. However, patient-reported outcome measurements of quality are inherently difficult to register when the patient is actively dying. Currently, no definite set of quality indicators exists to describe all aspects of the quality of care of dying patients. Most of the indicators used in the present study closely resemble those assessed as applicable or useful by Raijmakers et al in their literature update and experts' evaluation of quality indicators for end-of-life care of cancer patients [24].

Although, in our study, each questionnaire was filled out shortly after the patient's death by the responsible nurse/physician, the risk of misclassification of outcome, e.g. over- or underestimating the information given to

patients or families, cannot be ruled out. This risk is, however, probably unrelated to patient age and therefore unlikely to be an important threat to the validity of the study. Moreover, and importantly, the end-of-life questionnaire specifically requires that only information documented in the patient records is registered. With respect to individual items of the questionnaire, questions regarding decision making, palliative care consultations and prescribed drugs had a very high percentage of distinctive answers ('yes' or 'no') leading to a low drop-out level from the analyses (1–4%). Hence, the data on these aspects of the EOL care were particularly strong. In contrast, the drop-out percentage (i.e. 'do not know' answers) was higher for questions about patient information (16%) and bereavement support (17%) and, in particular, for the actual in relation to the preferred place of death (35%). Therefore, these latter data should be interpreted with some caution.

We know that, in specialised palliative care the registrations in the SRPC are more often done by physicians as compared to other types of care units where the registrants tend to be nurses. We cannot completely rule out the possibility that nurses and physicians might have answered questions on the delivery of palliative care differently. However, detailed information about the content of care as well as about prescribed drugs is readily available in the medical records and is accessed daily by nurses as well as by physicians as part of routine care. Moreover, potential differences due to characteristics inherent to different care types were controlled for in this study by adjusting for type of end-of-life care.

The SRPC covers a large majority of deaths from all parts of Sweden including all socioeconomic groups,

ages and care facilities. Nevertheless, 19% of all cancer deaths in Sweden during the study period were not reported to the SRPC. We cannot know for sure if the association between age and quality of end-of-life care in that group differs from the association found in this study. However, we consider any substantial difference unlikely due to the consistency of our findings.

Furthermore, we cannot rule out that, a possible difference in frequency or severity of EOL symptoms could have been present between elderly and younger cancer patients in this study. If so, that would likely have affected the propensity to involve palliative care consultation services in the care, and possibly the willingness to screen for symptoms or prescribe essential drugs for PRN injection. Nevertheless, proactive PRN prescriptions and symptom screening, as well as the other aspects of EOL care that this study did address, are considered standard care when treating dying patients. Whether our results on age as a determinant of care quality in the last week of life are generalisable to diagnoses other than cancers is unknown. We chose to specifically investigate cancer deaths since they occur in all age spans and underlie a majority of the deaths reported to the SRPC and, also, to minimise heterogeneity of our study population.

Finally, this study only addressed the care provided during the last week of life, and the results should not be extrapolated to palliative cancer care in general.

In conclusion, we have shown that increasing age is associated with inferior quality of end-of-life care among cancer patients in Sweden. This highlights an important aspect of inequality within contemporary palliative cancer care that needs to be addressed and counteracted.

## 5. Contributors

ML formulated the hypothesis, analysed the data, was the principal writer of the manuscript, and was responsible for the submission. BT was responsible for the statistical analyses and gave constructive input during the writing of the manuscript. SL contributed to study design, data analysis, gave constructive input and criticism on data interpretation, and took part in writing the manuscript. All authors contributed to the final version of the manuscript.

## Conflict of interest statement

None declared.

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## Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at <http://dx.doi.org/10.1016/j.ejca.2015.04.001>.

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