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Elderly gynaecological cancer patients at risk for poor end of life care: a population-based study from the Swedish Register of Palliative Care

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ABSTRACT

Introduction: Poorer end-of-life (EOL) care for elderly cancer patients has been reported. We assessed the impact of age on 13 indicators for the quality of EOL care as well as adherence to 6 national quality indicators in gynaecological cancer patients.

Methods: Age-dependent differences in 13 palliative care quality indicators were studied in gynaecological cancer patients registered in the population-based Swedish Register of Palliative Care. Association between the patient's age and each quality indicator was analyzed by logistic regression, adjusted for place of death where appropriate. Adherence to six national quality indicators determined by the Swedish National Board of Health and Welfare was estimated in all patients.

Results: We included 3940 patients with the following age distribution: 1.6% were 18–39 years of age, 12.3% 40–59 years, 37.2% 60–74 years, 28.9% 75–84 years and 20% were \geq 85 years. Age-dependent differences in implementation rate were present for some of the 13 quality indicators. Compared to elderly cancer patients, younger patients were more likely to be cared for by a specialized palliative care service, more often informed about imminent death as well as assessed for pain. For most national quality indicators, the goal level was not met. Only for the 'on demand prescription for pain', the goal level was reached.

Conclusions: EOL care did not meet national quality indicators in this population-based data from Sweden, in particular in the elderly population. Elderly gynaecological cancer patients are at high risk of poorer EOL care without the involvement of specialized palliative care services. Palliative care services need to be implemented across all institutions of EOL care to ensure good and equal care.

Introduction

Gynaecological cancer (endometrial-, ovarian-, and cervical cancer) account for 11.3% of new cancer cases in all women in 2018 and taken together this group is the third most common female cancer. The majority of patients with advanced gynaecological cancer experience recurrence and die despite optimal anticancer treatment. Amongst them, ovarian cancer has the highest mortality and accounts for the fifth most common cause of cancer death among females [1].

For cancer patients, complex associations between age and end-of-life (EOL) care have been reported. Elderly cancer patients are less likely to be enrolled in palliative care programs, less likely to die at home or in hospice, and receive fewer nursing visits or physician house calls at the end of their lives compared to younger patients [2]. EOL care for patients with gynecologic malignancies may include futile treatments and invasive procedures [2–4] but we know little about content and quality of care in the final weeks of life. Furthermore, elderly cancer patients with long-term comorbidities will be an increasing population in the coming years, living longer due to optimal tumor-directed treatment. This elderly population will have different needs compared to younger patients [5]. Frailty in this population in addition to preexisting comorbidities often lead to complex trajectories and put them at increased risk of adverse events during anticancer treatment. Elderly will in particular need the support of specialized palliative care but have often less access to these services.

The Swedish Register of Palliative Care (SRPC), a nationwide population-based quality register, enables the assessment of important aspects of EOL care. The registry covers all counties and municipalities in Sweden and registration in SRPC has become one of the national quality indicators for cancer care in Sweden [6]. An analysis of all cancer deaths between 2011 and 2012 reported poorer EOL care in the elderly compared to the younger cohorts measured by valid quality indicators [7]. Since the nineties, the government has

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B Supplemental data for this article can be accessed here.

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prioritized EOL care equally to healthcare for acute lifethreatening diseases in Sweden. A government program that promoted palliative care in general was launched to improve quality of life in the elderly [8]. At the same time, the SRPC was promoted as a nationwide population-based source to monitor EOL [6,9]. The Swedish National Board of Health and Welfare developed quality indicators for EOL care in 2017 to assess current practice and provide a basis for health care planning and improvement of care. We herein study agerelated EOL care in gynaecological cancer patients in Sweden. The adherence to National quality indicators of EOL care was also assessed. We hypothesize that age-related differences still exist and that EOL care may not meet the standards determined by the Swedish National Board of Health and Welfare.

Material and methods

Study population

We identified all patients who died of gynaecological cancer between January 2013 and December 2016 in the SRPC. For registry data between 2013 and 2015 data were extracted on the 9th February 2018 and for data 2016 on the 10th May 2019. The registry is linked to cause of death data from the National Board of Health and Welfare. Death from gynaecological cancer was defined as having one of the following codes (International classification of diseases, ICD-10) reported as the underlying cause of death: C56 or C570 (ovary/fallopian tube/peritoneum); C541, C548, C549 or C55 (corpus); C538 or C539 (cervix); and C518, C519, C52, C578, C579 or C58 (other gynaecological malignancies). Patients who had gynaecological cancer but died of competing causes were not included. If death was reported as unexpected in the SPCR, no additional data were collected to the registry, and patients were excluded from further analysis. Following the methodology of the previous report [7], we also excluded patients where expectedness of death was given as 'unknown'. The study population was then categorized in five pre-defined age categories: 18-39 years of age (n = 62), 40–59 years (n = 485), 60–74 years (n = 1466),75–84 years (n = 1139) and ≥ 85 years (n = 788).

Outcome assessments

Information in the registry is based on online questionnaires completed retrospectively by the nurse and/or physician responsible for the patient's EOL care. The questionnaire contains indicators of the quality of care in the last week of life. It underwent major revisions in 2011 and 2018, and minor changes in April 2012 and October 2015 reflecting feedback from the healthcare professional and after-validity studies [10,11]. For the outcomes reported here, only the question regarding place of death was slightly changed in October 2015 to consider 'dying at home without specialized palliative care' a separate category. The majority of questionnaires (91%) are completed by nurses. In specialized care units, the proportion of registrations made by physicians is higher (26%) compared to hospitals (7%) and nursing homes (1%). The complete questionnaire comprises 30 questions that include information about the patient and family, symptom assessment and severity, prescriptions of essential drugs as needed (PRN), and the use of palliative consultation services. The items about symptom occurrence and symptom relief were not chosen as outcomes due to the insufficient validity of these items [10]. On the guestionnaires, the physician or/ and nurse answered 'yes', 'no' or 'don't know' to most of the 30 guality indicator-guestions. For the presence of pressure ulcers, the following alternatives were available: 'No', 'don't know', 'grade 1', 'grade 2', 'grade 3' or 'grade 4'. Thirteen of these indicators were used as outcomes in this study. Place of death was divided into four categories: nursing homes, hospital ward (without palliative specialization), specialized palliative care unit (home care, hospice or specialized palliative hospital ward), and other (including forms of home care without palliative specialization). Thirteen of these indicators were chosen for assessment of age-dependent differences following the report by Lindskog et al. [7] (Supplementary Table 1). For each of those indicators, we only included patients where the respective item was available in the registry.

We also studied the adherence to the six quality indicators determined by the Swedish National Board of Health and Welfare: Assessment of pain during the last week in life (goal level 100%), PRN prescriptions against pain (goal level \geq 98%), PRN prescription against anxiety (goal level \geq 98%), no grade 2–4 pressure ulcers at death (goal level \geq 90%), documented assessment of oral health (goal level \geq 90%) and information about imminent death (goal level \geq 98%). The latter quality indicator also takes into account whether next of kin was informed if the patient had lost the ability to take part in medical decisions.

Statistical analysis

Association between the patient's age and each indicator was analyzed by logistic regression, adjusted for place of death in all analyses except for when this was the outcome. Age was also assessed as continuous variable in adjusted for type of care.

Using the oldest age category (\geq 85 years) as reference, we calculated odds ratios (OR) with 95% confidence intervals (CIs) for answering 'yes' to each indicator. For the analyses of place of death by age group, we computed the proportions of patients in each type of care for the different age group. Differences in indicators across places of death in the elderly, were assessed by computing the proportion answering 'yes' to each quality indicator for each type of care amongst the oldest age group (≥85 years). For all outcomes, except for pressure ulcers, an odds ratio above 1 means that the quality indicator is more often met in the younger age groups compared to the oldest age group whereas an OR below 1 means that the indicator is less often met in the younger age groups. For 'pressure ulcers', an OR below 1 means that the younger age groups more often met the indicator (i.e., less often had pressure ulcers) compared to the oldest age group whereas an OR above 1 means the younger patients less often met the indicator, had more pressure ulcers, compared to the oldest.

Adherence to the Swedish National Board of Health and Welfare quality indicators are given as proportions out of the total number of expected deaths reported to the SRPC. For the calculation of these proportions, 'don't know' answers were merged with 'no' answers [12].

Ethics and data permission

The study was approved by the Regional Ethical Review Board in Umeå, Sweden (registration number 2017/454-31). The SRPC management group approved the study plan and data access for 2013–2015 on 26th January 2018 and the additional access to data for 2016 on 30th April 2019.

 Table 1. Underlying causes of death in the study population of gynecological cancer patients.

	ICD-10	No. of	Total no.
Tumor site	code	cases	of cases
Cervix uteri	C538	4	478
	C539	474	
Corpus uteri	C541	72	1092
	C548	1	
	C549	485	
	C55	534	
Ovary/fallopian tube/peritoneum	C56	1838	1953
	C570	115	
Other	C518	2	417
	C519	180	
	C52	31	
	C578	0	
	C579	203	
	C58	1	
Total		3940	3940

Results

Study population

From 2013–2016, 4340, 4344, 4388 and 4288 units reported patients to the registry yearly. The coverage of cancer deaths during this period was 84.1, 88.9, 86.7 and 86.0%, respectively. We identified 4091 patients who had died from gynae-cological cancer. The following patients were excluded: One was <18 years old, in two patients a post-mortem examination indicated an unnatural cause of death, 108 patients had died unexpectedly, and 40 cases were reported as 'unknown'. Thus, a total number of 3940 patients with the following age distribution were included in the study: 62 patients (1.6%) 18–39 years of age, 485 patients (12.3%) 40–59 years, 1466 patients (37.2%) 60–74 years, 1139 patients (28.9%) 75–84 years and 788 patients (20%) >85 years.

All identified underlying causes of death are shown in Table 1. Completeness of the registered items was excellent with mean 96.65% (range 91.0 - 100%). For the 2970 patients with available information on time of completion of questionnaires, the time from death to data entry online was median 6 days (standard deviation 31.1 days).

General characteristics of EOL care

The major places of death of gynaecological cancer patients were hospitals, nursing homes, general or specialized palliative home care, and specialized palliative care in-patient units. Almost half of the patients died in specialized palliative care units (49.7%), 21.7 and 21.9% in nursing homes and at hospital, respectively, and 6.8% were registered with 'other place of death'.



Figure 1 shows the age-related trends with respect to place of death. It was more common for younger patients to die in specialized palliative care units while elderly patients more commonly died in nursing homes. Almost half of them died in nursing homes (47%) as opposed to only 5% of the patients in the youngest age category (18–39 years). Compared to the reference age group (\geq 85 years), younger patients were more often died in a palliative care unit (Table 2). For all age groups, these associations were statistically significant. For patients who died in general healthcare units without palliative care team was consulted in the care of younger patients compared to patients \geq 85 years with decreasing OR with increasing age.

Information and bereavement support

Younger patients were more often informed about imminent death than elderly patients with decreasing OR with increasing age. Yet, there was no consistent age-dependent difference associated with age when we studied the information given to families and caregivers about shifting care or imminent death.

Medical decision-making and preparedness for EOL care

There were age-dependent differences for fluid management and documented pain assessment toward EOL. Younger patients were more likely to receive fluids *via* enteral tube or intravenously during the last 24 h of life. There was also a trend toward more pain assessment documented compared to the oldest age group (Table 2). No age-dependent differences were shown for the assessment of other symptoms.

Younger patients were more likely to have injections prescribed against nausea and anxiety, but the estimates were not statistically significant in all age groups, probably due to the limited number of patients in the youngest age groups. Younger patients were more likely to have oral health assessed. All associations between age group and EOL care are given in Table 2.

Due to the significant age differences in the place of death, we assessed the proportion of patients meeting each indicator according to place of death in the oldest patients (\geq 85 years of age) (Figure 2). For key items, a larger proportion of elderly patients received better care when cared for in a palliative care unit as opposed to a nursing home. They were more often informed about imminent death (93 versus 76%) and assessed for pain (63 versus 43%) as well as oral health (92 versus 81%). Only 18% of the elderly patients who died in nursing homes had a palliative care consult documented.

Adherence to quality indicators according to the Swedish National Board of Health and Welfare

For most of the quality indicators defined by the Swedish National Board of Health and Welfare, the goal level was not met (Table 3). The goal was only reached for the on-demand

prescription for pain, with 98% of patients having a documented PRN prescription. Information about imminent death was given to 80% of patients, compared to a goal level of \geq 98%. Only 49% of the gynaecological cancer patients were assessed for the presence of pain during their last week of life. Further, an oral health assessment was only documented in 56% of the patients. In our analysis, 85% showed no signs of severe pressure ulcers, which is close to the goal level of \geq 90%.

Discussion

The quality of EOL care is in general poor according to this national data from Sweden, in particular in the elderly population. Despite national and international recommendations [12,13], palliative cancer care is not integrated into public cancer care. These findings may necessitate major shifts not only in the planning of public cancer care due to a growing elderly population, but also indicate the need for targeted palliative care education in public care.

We assessed for the first time age-related patterns in the quality of EOL care in gynaecological cancer patients in a national population-based study. For some of the 13 indicators, there were clear patterns of sub-optimal care with increasing age, including reduced probability of care in specialized palliative care units and the assessment for pain, one of the key symptoms near end of life. Across all age groups most national quality indicators for EOL were not met, including the assessment of pain and the provision of information to the patients and their families about imminent death.

It is estimated that the proportion of patients who require palliative care services will increase by 25-42% in 2040 [5]. Due to population aging, palliative care of the elderly is a growing public health issue and cancer is amongst the drivers for palliative care needs. An earlier report [7] revealed significant age-dependent differences in EOL care across different cancer types from 2011 to 2012. For most indicators, elderly patients were at higher risk of poor care, including the assessment of common symptoms as well as medical decision-making and the prescription of PRN medications against symptoms such as pain, anxiety and nausea. However, the report did not provide detailed data by cancer type and a direct comparison with our data is therefore difficult. Compared to the earlier report, fewer indicators showed age-dependent variation, which may indicate an improvement in care of the elderly. Since 2012, several actions that aim to improve EOL care in the elderly have been made in Sweden. In addition to the release of national palliative care guidelines, the Swedish government invested heavily in the elderly sick population ('Bättre liv för sjuka äldre') and the SRPC was granted additional financial support. These governmental programs may have facilitated standardized EOL care plans for the elderly. The overall availability of PRN prescriptions against the most important EOL symptoms underlines that core principles of EOL care are also followed in end of life institutions not specialized in palliative care. The finding that the majority of elderly gynaecological cancer patients

Table 2. Association between quality indicators and age.

Outcome ^a	Age group	OR	95% Cl	<i>p</i> -value
Informed about imminent death	18–39	3.9	1.2–13	.03
	40–59	2.7	1.8-4.2	<.001
	60-74	1.9	1.4–2.5	<.001
	75–84	1.3	1.0–1.7	.04
	≥85 Cantinuaua	Ket		
Information given to families about imminent death		< 0.001	0740	10
mornation given to families about infinitent death	40_59	J.4 1.4	0.7-40	.10
	60-74	1.4	1 2-2 4	.10
	75-84	1.2	0.8–1.7	.35
	<u>≥</u> 85	Ref		
	Continuous	0.002		
Fluids during the last 24 h	18–39	2.8	1.4–5.7	.005
	40–59	3.0	2.1–4.4	<.001
	60-74	2.0	1.5-2.8	<.001
	/5-84 _95	1.0 Pof	1.1-2.2	.01
	≥oo Continuous			
Assessment of pain	18–39	0.001	05-16	74
	40-59	1.4	1.1-1.7	.02
	60-74	1.2	1.0-1.5	.05
	75–84	1.2	1.0-1.5	.05
	<u>≥</u> 85	Ref		
	Continuous	0.101		
Assessment of other symptoms	18–39	0.7	0.4–1.4	.35
	40-59	1.1	0.8–1.4	.50
	60-74	1.1	0.9-1.4	.40
	/J-84 >85	1.U Rof	0.8-1.3	.90
	≥os Continuous	0.893		
Pressure ulcers	18–39	0.8	0.4-1.5	.51
	40–59	0.9	0.7–1.2	.44
	60–74	1.1	0.9-1.3	.44
	75–84	1.2	1.0-1.5	.07
	<u>≥</u> 85	Ref		
	Continuous	0.071		
Oral health assessment	18–39	0.5	0.3-0.9	.03
	40-59	0.6	0.5-0.9	.007
	75-84	0.0	0.0-1.0	.00
	>85	0.5 Ref	0.7-1.2	
	Continuous	0.001		
Injections prescribed as needed against pain	18–39	b	b	1.00
	40–59	3.2	0.9–11	.07
	60–74	1.1	0.6-2.0	.86
	75–84	1.7	0.8–3.3	.15
	<u>≥</u> 85	Ref		
	Continuous	0.168	05.44	10
injections prescribed as needed against nausea	18-39	1.5	0.5-4.4	.49
	40-39	1.7	1.0-2.0	.03
	75-84	1.5	0.8-1.5	.50
	>85	Ref		100
	Continuous	0.017		
Injections prescribed as needed against anxiety	18–39	1.7	0.4–7.5	.47
	40–59	1.9	1.0-3.5	.06
	60–74	1.7	1.1–2.7	.02
	75-84	1.5	1.0–2.4	.06
	≥85 Cantinuaua	Ref		
Injections proscribed as peopled against death rattle		0.049	03-22	67
injections preschoed as needed against death fathe	40-59	0.0 1 0	0.5-2.2	.07 QQ
	60-74	1.0	0.8-1.6	.65
	75-84	1.2	0.8-1.7	.36
	285	Ref		
	Continuous	0.752		
Death at a specialized palliative care unit	18–39	4.8	2.8-8.3	<.001
	40–59	4.8	3.8-6.1	<.001
	60-74	3.2	2.7–3.9	<.001
	75-84	2.2	1.8–2.6	<.001
	<u>></u> 85	Ket		
	Continuous	< 0.00 I		

(continued)

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Table 2 Continued

Outcome ^a	Age group	OR	95% Cl	<i>p</i> -value
Palliative consultation ^c	18–39	5.5	2.3–13	<.001
	40–59	3.9	2.7–5.7	<.001
	60–74	2.5	1.9–3.3	<.001
	75–84	1.8	1.4–2.4	<.001
	>85	Ref		
	Continuous	< 0.001		

^aAll outcomes except 'cared for by specialized palliative care' and 'palliative consultation' were adjusted for place of death.

^bAll patients in the youngest age category had injections prescribed as needed against pain.

^cOnly those patients who died outside of specialized palliative care units were included here.



Figure 2. Quality indicators in the elderly (285 years) across care levels.

Table 3. Adherence to quality indicators according to the Swedish National Board of Health and Welfare.

Quality indicator	Goal level (%)	Adherence in study population (%)
Information about imminent death	≥98	80
Assessment for pain	100	49
Documentation of oral health assessment	\geq 90	56
No signs of severe pressure ulcers (grades $2-4$)	\geq 90	85
On demand prescription for pain	≥98	98
On demand prescription for anxiety	≥ 98	96

died without the involvement of palliative care is still concerning. Comorbidities and potentially also impaired cognitive function in elderly patients add to the complexity of care and may also be a barrier to include them in important EOL discussions about imminent death as shown here. Another explanation maybe that cancer-related death in this age group is anticipated as expected and less traumatic by the health care staff. A belief in age-dependent differences

in the prevalence or severity of end of life symptoms in the elderly may contribute to some of the observed differences. Services need to be prepared for the dramatic increase in multi-morbidity as well as the longer survival with metastatic disease, and we therefore need to improve our understanding of the palliative care needs of elderly multi-morbid patients. A cancer diagnosis may aggravate preexisting symptoms in the multimorbid elderly such as weakness, poor mobility and poor appetite. It is predicted that care homes will be the most common place of death by 2040, and it is crucial to meet the demands of elderly cancer patients [14] in these institutions. An expansion of specialized palliative care teams also in nursing homes seems important as well as the development of care supported by guidelines and clinical skills responsive to the different patterns of symptoms in the multimorbid elderly. The evaluation and monitoring of patient-reported outcome measures (PROMS) would help to understand what patients and their caregivers expect from EOL care and how they perceive the care. In addition to these actions specifically

targeting aspects of palliative care, knowledge and skills on palliative care in general need to be improved among all health care providers. It is recommended to include palliative care into the curriculum of medical students and medical oncologists as well as introduce mandatory rotation to palliative care clinics [13].

National goals for palliative care were first published in 2017 [12] but until 2016 the majority of these national care goals were not met. The lack of assessments for pain in the last weeks of life and lack of information about imminent death is concerning. The latter also implies that information can be given to next to kin if the patient is suffering from cognitive impairment. Thus, the high goal level may still be justified even if some patients simply do not wish to receive that information. Our study underscores the importance of collecting and assessing quality of care in a population-based registry to identify gaps of care and longitudinal analysis of SRPC data will be important to assess improvement in adherence to quality indicators, even though they may not reflect all aspects of good care. Systematic analyses have already led to the implementation of palliative care guidelines and governmental support that specifically aim to improve elder care, including a temporary monetary bonus for counties and municipalities reporting to the SRPC. Structured care pathways such as the Liverpool care pathway (LCP) have been developed to enhance patient-centred decision-making and meet patients' physical, psychosocial, and existential needs in the last days of life [15]. Although there is a lack of high-quality studies on the efficacy of the LCP, especially for the elderly and patients dying in nursing homes [16], the launch of a national care plan for palliative care (Nationell vårdplan för palliative vård – NVP), reminiscent of the LCP, in late 2016 may further improve care for the elderly.

The population-based data and the high rate of data completeness for most items assessed are the strengths of this study. Yet, the study included only information from health care providers. Neither patient-reported outcomes (PROs) during EOL nor the patients' families' experiences were assessed. Our study assessed mainly care processes and only to a lesser degree outcome measures. However, this focus is in line with previous reviews [17,18] and only these indicators can be readily assessed in the SRPC [7]. As no further information of EOL is collected in the registry for patients dying unexpectedly, the patients were excluded from the analysis. Due to the posthumous reporting of indicators, misclassification bias can occur if outcomes are not registered correctly. However, it is unlikely that these differ by age group and, therefore, they may not threaten the validity of our results. More importantly, some items may simply lack documentation in the patient's medical records even though they have been assessed at bedside (i.e., oral health). Potential confounders like demographic characteristics such as education and socio-economic status could not be controlled for, as these are not registered in the SRPC.

In conclusion, EOL care in gynaecological cancer patients in general did not meet national quality indicators in this population-based data from Sweden. Older age is a risk factor for poorer end of life care, without the involvement of specialized palliative care services. Contemporary palliative care guidelines need to be totally integrated into all cancer care guidelines where the primary focus is anticancer treatment. The implementation of palliative care services in all institutions of EOL care is necessary to ensure good and equal care, independent of age. Probably the most important initiative needs to be taken by national and regional health care stakeholders by focusing on and allocating more resources to EOL care. This will also demand to prioritize the growing elderly population.

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Disclosure statement

The authors have no conflicts of interest to declare.

Author contribution

KL and DL led the project. KL, DL and LM developed the concept of the study. All authors contributed to the analysis plan. LM received the SRPC data and performed the data analysis. All authors contributed to interpreting the data, writing and reviewed the manuscript.

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