

Quality of care for the dying across different levels of palliative care development: A population-based cohort study

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Maria EC Schelin^{1,2}, Bengt Sallerfors^{1,2}, Birgit H Rasmussen^{1,3} and Carl Johan Fürst^{1,2} 

Abstract

Background: There is a lack of knowledge about how the provision and availability of specialized palliative care relates to the quality of dying in hospital and community-based settings.

Aim: We aimed to explore the quality of care during last week of life in relation to different levels of palliative care development.

Design: We investigated access to palliative care in Southern Sweden, where one region offers palliative care in accordance with European Association for Palliative Care guidelines for capacity, and the other region offers less developed palliative care. Data on approximately 12,000 deaths during 2015 were collected from the Swedish Register of Palliative Care. The quality of care was investigated by region, and was measured in terms of assessment of oral health and of pain, and end-of-life conversation, companionship at death and artificial nutrition/fluid in the last 24 h.

Results: The overall quality of care during last week of life was not consistently better in the region with fully developed palliative care compared with the less developed region. In fact, for patients dying in hospitals and community-based settings, the quality was statistically significantly better in the less developed region. The small proportion of patients who had access to specialized palliative care had superior quality of care during the last week of life as compared to patients in other care settings.

Conclusion: The capacity of specialized palliative care does not per se influence the quality of care during the last week of life for patients in other settings.

Keywords

Palliative care, quality of care, population

What is already known about this topic?

- The European Association for Palliative Care has established guidelines for the provision for specialized palliative care (PC).
- Specialized palliative in-patient and home care does benefit patients, especially those with cancer.

What this paper adds?

- The study demonstrated that the overall quality of care during last week of life in a region with fully developed PC capacity was not consistently better compared to a less developed region.
- For patients dying in hospitals and community-based settings, the majority of quality indicators scored significantly better in the less developed region.

¹Institute for Palliative Care, Lund University and Region Skåne, Lund, Sweden

²Department of Clinical Sciences Lund, Faculty of Medicine, Lund University, Lund, Sweden

³Department of Health Sciences, Faculty of Medicine, Lund University, Lund, Sweden

Corresponding author:

Carl Johan Fürst, Institute for Palliative Care, Medicon Village, S-223 81 Lund, Sweden.

Email: carljohan.furst@med.lu.se

Implications for practice, theory or policy

- Regarding the optimal organization of PC, a sole focus on specialized PC capacity is insufficient to meet the needs of patients and families at the end of life.
- To increase availability and quality of PC, future development must include specialized PC outreach activities, for example, PC consultations, rounds and education.
- An important topic for clinical development and future research will be to identify effective mechanisms to facilitate knowledge transfer from specialist to general PC.

Introduction

There is an increasing discrepancy between the need for and supply of palliative care (PC). It is likely that about 69%–82% of people dying in high-income countries would benefit from PC.¹ There has been a significant change in the place of death, from the hospital and home to nursing homes, between 1987 and 2011, as reported in a recent Norwegian study.² The trend has been mainly due to the ageing of the population and epidemiological changes, with increased mortality due to cancer and dementia and a decrease in circulatory diseases.² A similar pattern by 2040 has been predicted for the United Kingdom.³ According to Gómez-Batiste et al.,⁴ ‘the current response to these challenges is largely specialized palliative care’.

PC is traditionally described as *general* when provided by hospital units, general practitioners (GPs), district nurses, or care home staff, and *specialized* when provided by teams of professionals specifically trained in PC. Specialized PC may be provided in dedicated in-patient settings (e.g. hospices), home care settings and by hospital support teams.⁵ Most research on the benefits of PC for patients and families has been conducted in the context of specialized PC, where mounting evidence suggests that specialized PC does significantly improve patient outcomes in terms of quality of life and general symptom burden,⁶ pain, anxiety and reduced hospital admission,⁵ and patient and caregiver satisfaction with care.⁶ Improved experience of security when cared for by palliative home care teams has also been reported.⁷

However, and importantly, there is a lack of population-level studies investigating the provision and availability of specialized PC in relation to the quality of care in last week of life in other care settings, such as hospitals and community-based settings, including long-term care facilities. Despite these uncertainties, there have been many attempts and plans to implement specialized PC in Sweden and internationally without in-depth knowledge of the effectiveness and impact of different models of services and skill mixes within teams.⁵ Furthermore, evaluations of PC provision nationally⁸ or internationally, such as the European Association for Palliative Care (EAPC) Atlas of Palliative Care in Europe⁹ and the ‘2015 Quality of Death Index’,¹⁰ point out important differences in the provision and availability of PC at a population level, for example, in

national-level policies and guidelines, community awareness and engagement and integration of PC into existing health care structures. A recent review of reviews concluded that further primary studies are required that assess models of care.¹¹

Aim

In accordance with social dynamics and the concept of critical mass, it is assumed that fully developed PC with broad availability within a region would spill over to care of the dying in community-based settings and hospitals in that region. The primary mechanism for this would be that the patients with the most complex needs would be referred to specialized PC, thereby leaving more resources to the remaining patients. Other mechanisms include outreach activities/consulting, and educational activities by the specialized PC units towards the community-based settings and hospitals. Furthermore, it cannot be excluded that if enough staff, patients and policy makers adopted the principles and attitudes of PC, that is, a PC approach, this would spread throughout the care services through informal knowledge and awareness dissemination.¹²

The aim of this study was therefore to explore the overall quality of care during last week of life in relation to the level of PC development in different regions.

Methods

Organization

Southern Sweden has a population of about 2 million¹³ and consists of four counties: Skåne, Blekinge, Kronoberg and Halland. Within this area, we investigated access to PC. We obtained data relating to the health care organization and resources through structured interviews with the health care official responsible for PC in each of the four counties. Questions were sent beforehand, in order to facilitate well-researched answers. These interviews were performed, during the spring of 2016, by one of the authors (B.S.) with extensive experience in health care evaluation. The results were thereafter structured and summarized. Each official reviewed the findings and had opportunities for correction. The resulting report was presented to the governing organ of Health Care of Southern

Table 1. Characteristics of the regions with fully developed versus less developed palliative care.

	Region	
	Fully developed	Less developed
Organization type	Autonomous	Part of hospital clinic
In-patient palliative care settings (<i>n</i>)	6.1	1.5
Palliative home care settings (<i>n</i>)	21.9	15.1
Consultations (<i>n</i>)	988	616
Physicians (<i>n</i>)	2.9	2.2
Nurses (<i>n</i>)	21.1	5.1
Assistant nurses (<i>n</i>)	5.3	0
Other care workers (<i>n</i>)	3.9	0.4
Palliative physician and nurses on call around the clock	Yes	No
2015 characteristics of the population of the two regions		
Number of inhabitants	1,301,571	661,030
Number of inhabitants > 70 years (% of total population)	165,130 (12.7)	94,342 (14.2)
Number of deaths (% of total population)	11,800 (0.91)	6335 (0.96)
Percentage of population with maximum 10 years schooling	17.3%	18.8%
Percentage with income below the limit for state income tax	93%	93%
Percentage of population living in urban area (pop > 200)	90%	82%

Numbers are given per 100,000 inhabitants.

Information on the population of the two regions collected from Statistics Sweden.¹⁷

Sweden and is available online (in Swedish).¹⁴ Once the report was finalized, the information was used to judge the level of PC in each county with the goal to classify each county as having fully, or less, developed PC. In this study, we use the concept of ‘fully developed palliative care’ to conceptualize the EAPC White Paper guidelines for PC services: one home care team per 100,000 inhabitants, one hospital support team per 250 beds and in-patient PC services with 50–100 beds per 1,000,000 inhabitants.^{12,15} The collected information resulted in the classification of one region, covering one county, as having fully developed PC and another region, covering three counties, as having less developed PC. This classification also corresponds to availability of around the clock (24/7) services,¹⁶ which was only present in the fully developed region. During the study period, the EAPC White Paper guidelines^{12,15} in relation to outreach activities/consulting and educational activities by specialized PC towards the community-based settings and hospitals were in an initial stage of development. The majority of referrals to specialized PC were from hospital medical specialists. Few referrals were from GPs and the organization did not allow for self-referrals. Shared care or triage did rarely occur.

As described in Table 1, the regions with fully and less developed PC were significantly different regarding organizational resources. The region with fully developed PC had an autonomous organization led by a manager while the PC in the less developed region was delivered by a hospital clinic (surgery, oncology or internal medicine). The fully developed PC service also had larger capacity in terms of in-patient PC services, home care teams

and hospital consultations, and a number of health care workers of all categories including palliative physicians and nurses available around the clock. The less developed region differed substantially in terms of services. Only one county had in-patient beds for specialized PC and these were integrated with another department. Two counties carried out specialized PC in the patient’s home in close collaboration with nurses from the municipality and one had hardly any home care. One had almost purely consultative activities, while these were almost absent in another. In terms of general characteristics, the fully developed region has approximately twice the population compared to the less developed region and is more urbanized. Income and education level are largely similar in the two regions, as is the proportion of the population that are >70 years of age.

Patient population

To compare the organizational definitions of fully and less developed PC with the resulting quality of care in each region, we collected information on patients from the Swedish Register of Palliative Care (SRPC).¹⁸ The SRPC started in 2005 and by 2015 had a national coverage of 66%, but with the final aim to include all dying people, regardless of diagnosis and care settings.¹⁹ The SRPC is based on an end-of-life (EoL) questionnaire²⁰ inspired by the 11 principles constituting a good death and dying from British Geriatric Society guidelines.²¹ The EoL questionnaire contains 30 questions out of which one is a structure, eight are process and eight are outcome indicators. Altogether,

they concern the quality of care primarily during the last week of life. The questionnaire is completed by the health care professionals after the death of a patient. For questions on symptoms, the SRPC does not specify which assessment tool should be used, or otherwise specify the circumstances of the assessment.

We requested SRPC data on all patients reported to the register who died during 2015 in Southern Sweden.¹⁹ With an intent to select the most clinical relevant indicators, an outcome set of five quality indicators from the SRPC were chosen in consensus (before analysis) by a palliative multi-professional expert group within the region of Southern Sweden, including the authors. The five quality indicators selected were assessment of oral health, assessment of pain, EoL conversation, companionship at death and artificial nutrition/fluid in the last 24 h. The first three indicators are included in the Swedish National Quality Indicators for Palliative care. The indicator of companionship at death reflects the negative connotation of dying alone and a general fear of a bad death.²² The withholding of artificial nutrition/fluid in the last 24 h is perceived as good clinical practice and as a relevant quality indicator for care of the dying in Sweden.²³

Analysis

The statistical analysis was descriptive. For each of the chosen indicators, we calculated the proportion of patients with the negative outcome (*lacking* oral health assessment, *lacking* an EoL conversation, *lacking* pain assessment, *lacking* companionship at death, *having* artificial nutrition/fluid in the last 24 h of life). The proportion of patients with each indicator outcome was tested with chi-square test with 0.05 as the alpha level. All analyses and data management were performed in SAS version 6.1 (SAS Institute, Cary, NC, USA).

Swedish law requires permission from an ethical review board before any research is initiated, if it includes personal data with information that can be linked back to the person. However, when a person is deceased, the data are no longer classified as personal data in the legal sense and are thus no longer covered by the ethical review board mandate and are not protected. The data delivered from the SRPC were de-identified.

Results

During 2015, a total of 11,996 patients from Southern Sweden were entered in the SRPC,¹⁹ which corresponds to 67% of the deceased in the study area for that year. After excluding 1891 patients whose death was unexpected and for whom the register had therefore not requested data, our analysis dataset consisted of 10,105 patients. Their mean age was 82 years and 54% were female. Altogether 6402 (63%) of all deaths occurred in the region

with fully developed PC, while 3703 (36%) occurred in the region with less developed PC. In total, 1994 (20%) were reported as having died in specialized PC (at home or at the in-patient unit), while 4752 (47%) died in community-based settings and 3359 (33%) in hospitals.

Table 2 shows a comparison between the region with fully developed PC and the region with less developed PC regarding the five chosen indicators of quality of care. There is no consistent pattern of PC overall being of higher quality in the fully developed region. Only two of the five indicators, artificial nutrition/fluid in the last 24 h of life (15.3% vs 17.7%) and not having an EoL conversation (38.7% vs 43.2%), scored better in the fully developed region. By contrast, the proportion of patients lacking an oral health assessment and lacking a pain assessment was very similar between the two regions, and the proportion of patients lacking companionship at death was lower in the less developed region (14.9% vs 16.5%).

Moreover, the quality of care during last week of life in the community-based settings was higher in the less developed region compared with the fully developed region for all indicators except artificial nutrition/fluid in the last 24 h of life. These differences were statistically significant. Also, for three of the five indicators (oral health assessment, pain assessment and having an EoL conversation), the quality of care during last week of life delivered in hospitals was statistically significantly higher in the less developed region than in the fully developed region. For the remaining two indicators (companionship at death and artificial nutrition/fluid in the last 24 h of life), there was no statistically significant difference.

In Table 3, the analysis was restricted to the fully developed region ($N = 6402$). Table 3 compares quality of care during last week of life in specialized PC units versus community-based settings and hospitals. For all indicators (except companionship at death), the specialized PC unit delivered higher quality of care, that is, the proportion of patients lacking good quality care was statistically significantly lower. Regarding companionship at death, there were no statistically significant differences between community-based settings and specialized PC.

In Table 4, these results were stratified by whether the cause of death included cancer. With regard to the proportion of patients lacking an EoL conversation, pain assessment and/or companionship at death, the PC of patients with cancer was of higher quality in specialized PC and hospitals. In community-based settings, patients with cancer had better quality of care regarding EoL conversation and pain assessment compared to patients without cancer. Oral health assessment and artificial nutrition/fluid in the last 24 h of life were not statistically significantly different for patients with versus patients without cancer, in any of the care settings.

We further investigated the proportion of patients with high quality of care in specialized palliative in-patient

Table 2. Quality of care indicators comparing all care and care delivered in community settings and hospitals in the region with fully developed palliative care versus the region with less developed palliative care.

	Region		p-value
	Fully developed	Less developed	
<i>Patients (%) lacking</i>			
Oral health assessment			
All (N = 5735 resp 3245)	25.1	24.8	0.71
Community settings (N = 2516 resp 1824)	25.5	22.5	0.02
Hospitals ^a (N = 1509 resp 1175)	33.4	28.4	<0.01
End-of-life conversation			
All (N = 5730 resp 3223)	38.7	43.2	<0.01
Community settings (N = 2488 resp 1841)	44.9	38.1	<0.01
Hospitals ^a (N = 1520 resp 1137)	64.5	59.0	<0.01
Pain assessment			
All (N = 5905 resp 3386)	57.6	59.5	0.08
Community settings (N = 2623 resp 1915)	63.6	56.3	<0.01
Hospitals ^a (N = 1568 resp 1279)	84.9	66.6	<0.01
Companionship at death			
All (N = 6402 resp 3703)	16.5	14.9	0.03
Community settings (N = 2727 resp 2025)	12.5	9.4	<0.01
Hospitals ^a (N = 1944 resp 1415)	24.6	24.0	0.71
<i>Patients (%) having</i>			
Artificial nutrition/fluid in the last 24 h ^b			
All (N = 6336 resp 3652)	15.3	17.7	<0.01
Community settings (N = 2722 resp 2016)	1.6	3.3	<0.01
Hospitals ^a (N = 1883 resp 1373)	41.6	39.8	0.30

SRPC: Swedish Register of Palliative Care.

Note that number of patients refer to the minimum number of patients for each region. Due to differently missing data for the different indicators, the number of included patients for the developed region ranges up to N = 6402 and for the less developed region up to N = 3703. Categorization 'All' refers to all deaths in the respective region reported to the SRPC, irrespective of place of death.

p-values result from chi-square tests.

^aExcluding specialized palliative care units.

^bArtificial nutrition/fluid is usually not available in community-based settings.

Table 3. Indicators of quality of care delivered in the region with fully developed palliative care (PC) in different care settings: specialized palliative care, community-based settings and hospitals.

	Specialized PC	Community settings	Hospitals ^a	p-value
	N = 1712	N = 2488	N = 1509	
<i>Patients (%) lacking</i>				
Oral health assessment	17.3	25.5	33.4	<0.01
End-of-life conversation	6.9	44.9	64.5	<0.01
Pain assessment	23.3	63.6	84.9	<0.01
Companionship at death	13.7	12.5	24.6	<0.01
<i>Patients (%) having</i>				
Artificial nutrition/fluid in the last 24 h ^b	8.2	1.6	41.6	<0.01

Note that number of patients refer to the minimum number of patients for each setting. Due to varied and missing data for the different indicators, the number of included patients for the specialized PC ranges up to N = 1731, for the community settings to N = 2727 and for the hospitals up to 1944. When comparing only specialized PC and community-based settings, all results remained statistically significantly different ($p > 0.01$), except for companionship at death ($p = 0.26$).

p-values result from chi-square tests.

^aExcluding specialized palliative care units.

^bArtificial nutrition/fluid is usually not available in community-based settings.

Table 4. Indicators of quality of care delivered across the different care settings in the region with fully developed palliative care (PC), comparing patients with cancer to patients without cancer.

	Specialized PC		Community settings		Hospitals ^a	
	$N_{\text{Cancer}} = 1524$ $N_{\text{Non-cancer}} = 187$	<i>p</i> -value	$N_{\text{Cancer}} = 554$ $N_{\text{Non-cancer}} = 1934$	<i>p</i> -value	$N_{\text{Cancer}} = 410$ $N_{\text{Non-cancer}} = 1084$	<i>p</i> -value
<i>Patients (%) lacking</i>						
Oral health assessment						
Cancer	17.6		23.7		34.8	
Non-cancer	14.9	0.36	26.1	0.25	32.8	0.46
End-of-life conversation						
Cancer	5.7		22.0		42.7	
Non-cancer	15.9	<0.01	51.5	<0.01	72.5	<0.01
Pain assessment						
Cancer	22.3		55.7		75.9	
Non-cancer	31.6	<0.01	65.9	<0.01	88.3	<0.01
Companionship at death						
Cancer	12.4		10.7		20.2	
Non-cancer	24.1	<0.01	13.1	0.11	26.3	<0.01
<i>Patients (%) having</i>						
Artificial nutrition/fluid in the last 24 h ^b						
Cancer	7.9		1.8		42.1	
Non-cancer	10.5	0.23	1.5	0.61	41.5	0.81

Note that number of patients refer to the minimum number of patients for each setting and diagnosis. Due to missing data for the different indicators, the number of included patients for the specialized PC ranges up to $N = 1731/191$ for cancer and non-cancer, respectively. Correspondingly, for community settings, the number of patients ranges up to $N = 609/2118$ for cancer and non-cancer, respectively, and for hospitals the range is up to $N = 531/1413$ for cancer and non-cancer, respectively.

p-values result from chi-square tests.

^aExcluding specialized palliative care units.

^bArtificial nutrition/fluid is usually not available in community-based settings.

care compared with specialized palliative home care. For three of the five quality indicators: EoL conversation, pain assessment and companionship at death the home setting performed better, while for artificial nutrition/fluid in the last 24 h, the proportions were similar. Finally, the proportion of patients lacking oral health assessment was statistically significantly lower in the in-patient setting (data not shown).

Discussion

Through data from the SRPC register, we are able to provide a comprehensive understanding of the quality of care during the last week of life independently of care models and settings. The results dismiss our assumption that fully developed PC capacity with broad availability within a region would spill over to care of the dying in community-based settings and hospitals in that region. Actually, the overall quality of care during last week of life in the region with fully developed PC (i.e. meeting the EAPC guidelines regarding capacity¹⁵) was not consistently better compared with the less developed region. In fact, when looking specifically at patients dying in hospitals and community-based settings, the majority of the quality indicators scored significantly

better in the less developed region, compared with the fully developed region.

In the region with fully developed PC, patients dying in specialized PC had a higher level of quality of care compared with those dying in non-specialized PC settings. This result is consistent with the international literature reporting, specifically for patients with cancer, that specialized palliative in-patient and home care does benefit patients.^{5,24} Finally, we showed that the known difference in quality of care during the last week of life between patients with and without cancer mostly holds true in all care settings and can thus not be explained by the higher probability of patients with cancer receiving specialized PC.

One likely explanation for lack of spill over effect of a fully developed specialist PC capacity could be the developmental stage of outreach activities including consultation and educational activities by specialized PC towards the community-based settings and hospitals. Despite the evidence that early access to PC benefits patients and families,²⁴ referrals to PC are still limited to the terminal phase of illness.²⁵ Thus, as our findings showed, capacity in and of itself was insufficient to promote improvement at the population level. This indicates the necessity of outreach activities. Here, improvements have been shown when specialist

PC was integrated into existing practice through interdisciplinary teamwork,^{24,26} palliative consultations^{4,24} and palliative rounds.²⁷ Since palliative medicine recently has become a formal speciality in Sweden, a model for cooperation between specialized palliative medicine and other specialties is of importance as has been emphasized in other countries in the corresponding situation.²⁸ Educational activities including not only health care students and professionals but also patients, families and the public are necessary. Improvements have been reported on patient-level outcomes,²⁹ for example, in relation to education about prognostic awareness and EoL discussion about goals of care and understanding of the illness.^{29,30} Last but not least, activities are needed to improve people's preparedness for encounters with death, dying and mourning and be able to request quality EoL care. To reach this goal, clinical models of PC need to expand and include ideas from a public health perspective.^{31,32}

In PC over 300 quality indicators have been described, covering all domains conceptualizing quality in PC.^{33,34} This variation in outcomes measures may contribute to why PC research has failed to inform clinical practice^{35–37} and also hinders meta-analyses.¹¹ The SRPC is one of the few registries including quality indicators relevant to the last week of life¹⁹ and is the only registry collecting national patient outcome measures outside specialized PC.²⁰ The five quality indicators chosen in this study cover different important clinical aspects of care during last week of life: oral health assessment brings up aspects of quality nursing care. EoL conversation addresses patient and family participation. Assessment of pain reflects one of the core elements of symptom control in PC and is relevant to almost all patient groups. Companionship at death brings up both the social and existential dimensions of quality of care. However debated,³⁸ the final indicator, artificial fluid during the last 24 h, is a salient medical issue and mirrors patient/family/health care staff communication. Of note, three of the quality indicators, assessment of oral health, assessment of pain and having an EoL conversation, are process indicators rather than outcome indicators.^{39–42}

The major strengths of this study are the population-based setting, the large and recent (2015) data material and the fact that these data resulted from a real-world setting, as opposed to a trial. We believe that with a health care system such as the Swedish, which is tax-based and strives to provide equal access to health care, generalizability of the findings is good, as the health care organization rather than the resources of the patients themselves determine access to PC. All indicators were reported by health care professionals, which is likely to have decreased information bias and thus to have increased the validity of the results. We also note that the two compared regions are similar in terms of socioeconomic factors and proportion of elderly in the population. If the fully developed region's

slightly higher affluence affected our results, it would have been in the direction of higher quality of care in this region, which is the opposite of what we found.

Research findings can, however, never be better than the source of the data, which makes it relevant to bring up potential weaknesses of the SRPC, whose coverage is only 67% of all deaths in the studied geographical area and period. It cannot be excluded that the care units that choose to report to the register have a better quality of care than the units that choose not to report, while the opposite seems unlikely. Furthermore, a weakness of the SRPC is the risk for incorrect reporting of place of death. For example, a patient in a nursing home who receives care from a specialist palliative consultant may be reported as having received specialist PC. The proportion of patients misattributed like this is estimated by the SRPC to be 7.5% for 2015.

The results of this study are novel and as such should be regarded as preliminary until replication studies in other populations can be conducted. However, as pointed out by Brereton et al.,¹¹ in order to do such studies methodological obstacles as well as terminology needs to be taken into account. Furthermore, we note that when investigating factors with many potential effects, such as the organization of health care, we expect these effects to go in different directions. Thus, several true differences may even out and lead to an overall result of no difference. In addition, relatively few patients are cared for in specialized PC, which leads to decreased power to detect true differences.

Implications

Regarding the optimal organization of PC, our results suggest that an alternative strategy to a sole focus on specialized PC capacity can be equally successful in creating quality of EoL care. With the goal to increase availability and quality of PC, future development must include specialized PC outreach activities (including, for example, PC consultations, rounds and education) and providing PC early and through the use of screening tools to identify patients with unmet needs.⁴³ Furthermore, a readiness and motivation from hospitals and primary care to accept and integrate new knowledge and skills is needed. The future development could thus include an emphasis on improvement of general palliative home care, in terms of around-the-clock staff availability and increased competence in effective symptom control and skilful communication, as suggested by Sarmiento et al.⁷ Our results also emphasize and is in line with previous advocacy for improvements on a population level.³¹ One important topic for clinical development and future research will be to identify effective mechanisms to facilitate knowledge transfer from specialist to general PC.

In conclusion, in this large population-based study, we showed that meeting the EAPC recommendations for fully

developed PC capacity did indeed improve quality of care for the small proportion of patients with access to specialized PC; however, there was no effect for the vast majority of patients dying outside specialized PC.

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ORCID iD

Carl Johan Furst  <https://orcid.org/0000-0002-2406-6907>

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