

RESEARCH ARTICLE OPEN ACCESS

Assessing the Impact of Specialist Palliative Care on Healthcare Utilisation at the End of Life Among Patients With Pancreatic Cancer: A Nationwide Register-Based Cohort Study

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Received: 13 October 2025 | **Revised:** 8 April 2026 | **Accepted:** 24 April 2026

Keywords: end-of-life care | healthcare utilisation | pancreatic cancer | specialist palliative care

ABSTRACT

Introduction: Advanced pancreatic cancer is often a rapidly progressing malignancy causing high symptom burden. The objective of this study was to assess the association of specialist palliative care (SPC) and its timing with healthcare resource utilisation at the end of life.

Methods: This nationwide retrospective study which covers the whole population of Finland included all 1199 patients who died of pancreatic cancer in 2019. Data were obtained from national registries. Patients were categorised into two groups based on the timing of their first contact with SPC: Group I (> 30 days before death), and Group II (\leq 30 days before death or no contact).

Results: Among 1199 patients, 438 (36%) had a SPC contact, and median time from the first contact to death was 51 days. Contact with a SPC occurred > 30 days before death for 22.5% of the patients ($n=270$). Having an earlier contact with SPC (Group I) was significantly associated with fewer secondary care hospitalisations (25% vs. 56%, $p<0.001$) and fewer emergency department (ED) contacts (50% vs. 61%, $p<0.001$) during the last month of life. In addition, patients in Group I were more likely to receive hospital-at-home services (44% vs. 9%, $p<0.001$) and to receive care in SPC wards (23% vs. 5%, $p<0.001$). Most of the patients died in hospital (56% vs. 79%, $p<0.001$), but death in SPC ward (22% vs. 5%, $p<0.001$) or at home (19% vs. 13%, $p<0.014$) was more likely for patients in Group I.

Conclusion: Lower secondary healthcare utilisation and ED contacts during the last month of life, and higher probability of dying in SPC ward or at home, were observed in patients who had an earlier SPC contact. Integration of SPC in time should be ensured for all patients with advanced pancreatic cancer.

Liisa Rautakorpi and Nelli-Sofia Nähls contributed equally and share the first authorship.

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1 | Introduction

Pancreatic cancer is one of the leading causes of cancer-related deaths both in Finland and worldwide [1]. Although the development of targeted anticancer therapies has changed the landscape of treating many malignant diseases, the prognosis of pancreatic cancer patients has not improved notably [2]. The median overall survival (OS) of patients with pancreatic cancer is still often limited to months and 5-year OS is only 5%–13% [3, 4].

Patients with advanced pancreatic cancer often have a vast variety of symptoms and complications, such as biliary obstruction, duodenal obstruction, nausea, pain, or infections, and therefore this patient group is frequently in need of healthcare services during the last months of life [5, 6]. When the relatively short OS of this patient group is also taken into consideration, the need for specialist palliative care (SPC) services is warranted at an early stage of the disease trajectory [7]. Indeed, as European Society for Medical Oncology (ESMO) and American Society of Clinical Oncology (ASCO) guidelines state, early palliative care (PC) intervention should be offered to all patients with advanced pancreatic cancer, preferably as early as the first visit to oncological assessment [8, 9].

Early integration of PC has been associated with positive outcomes such as better symptom control and quality of life among patients with cancer [10, 11]. In addition, palliative intervention has been shown to decrease the use of aggressive anti-cancer therapies, ED visits, intensive care unit (ICU) admissions, and multiple hospitalisations as death approaches [12–14]. There are also reports showing that it may diminish the costs of care near end of life (EOL) [15]. The need for healthcare services during the last months of life is obvious for patients with pancreatic cancer but the type of services used should focus on primary care and SPC services close to the patient's home instead of secondary and tertiary healthcare [16]. The highly valued quality indicators of EOL care, by Earle et al., also support this, as multiple hospitalisations and ED visits during the last month of life have been stated to indicate overly aggressive care among patients with cancer [17].

The increasing use of healthcare services is known to be common during the last month of cancer patients' life which suggests that SPC duration of more than 30 days could be used as a clinically meaningful threshold when evaluating the impact of SPC on patients with pancreatic cancer [18, 19]. This approach has been used in previous studies assessing the effect of early SPC in cancer patients [12, 20, 21] and is in line with quality indicators suggesting that treatment in the last 30 days of life may be aggressive and potentially avoidable [17].

The aim of this nationwide study including the whole population of Finland was to assess the association of the timing of SPC contact with the use of healthcare resources during the last month of life in patients with pancreatic cancer. To our knowledge, previous nationwide data evaluating the EOL use of all healthcare services for patients with pancreatic cancer have not been reported.

2 | Methods

2.1 | Patient Selection and Data Collection

This patient cohort consisted of all 1199 patients with pancreatic cancer who died in Finland in 2019. Data were collected from the 2019 Causes of Death Register's data and the patients were identified using the International Statistical Classification of Diseases 10th Revision (ICD-10) code C25 for pancreatic neoplasm. Data on patient characteristics and ICD-10 codes for pancreatic neoplasm and palliative care in addition to the use of healthcare services were collected from national Care Registers and Kanta Services. The study was reported in accordance with the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines [22].

Cause, place, and time of death were obtained from the 2019 Causes of Death Register. The place of death was categorised as home (private housing), long-term care facility, hospital (including primary and secondary care hospitals), or SPC ward, the latter indicating death under dedicated SPC inpatient units, including hospices.

All the data, which were extracted from these different registries between 2018 and 2019, were linked using a personal identification number for each patient, after which the personal identification codes were replaced with research numbers to pseudoanonymise the data. The data collection process has been described in detail in previous publications [23–27].

2.2 | The Use of Healthcare and Social Care Services

To evaluate the use of healthcare and social care services, including PC services, data were obtained from the national Care Register and Kanta Services and then linked to a health service unit code list to further identify and classify all the care providers. All contacts to these units were included and each contact, clinic visit, and hospital stay (discharge) accounted for one contact.

Healthcare services included outpatient clinic contacts, hospitalisations, and ED contacts, including contacts with primary, secondary, and tertiary healthcare. Patients may have been treated simultaneously in various healthcare units and all these contacts were included despite the indication for treatment. In the analysis, these healthcare services were divided into primary care and secondary care, including secondary and tertiary care, for further analysis. Throughout this analysis, the categories of secondary and tertiary care are combined and presented collectively as 'secondary care'. Primary care hospitalisations refer to admissions to primary care inpatient units. Secondary care hospitalisations refer to admissions to secondary or tertiary care hospitals such as central hospitals or university hospitals. ED visits were counted as one entity. Social care service utilisation and home care service in addition to PC services were analysed as separate entities.

2.3 | Specialist Palliative Care Contact

In Finland, palliative care services and end-of-life care are provided at general or specialist levels according to the complexity of patients' symptoms and this study is focused on evaluating the impact of SPC. SPC is provided by multidisciplinary teams in secondary and primary healthcare, including PC outpatient clinics or wards, PC consultation services, hospices, and palliative hospital-at-home. Initial SPC contact may take place in any of these specialist care units. Each university hospital has a palliative care centre that coordinates the PC in the area.

To study the association of SPC with healthcare utilisation, patients were divided into two groups according to the timing of the first SPC contact: Group I (patients with first SPC contact >30 days before death) and Group II (patients with first SPC contact ≤30 days before death or no SPC contact). Based on previous studies, to allow sufficient time for patients to benefit from SPC in terms of the use of acute healthcare utilisation, and for this effect to be assessable during the final 30 days of life, patients with no or late SPC contact were analysed as a single group [21, 28].

2.4 | Ethics Statement

This study was conducted in collaboration with the Finnish Institute for Health and Welfare (THL) as part of the Project on Quality Information on Palliative Care and End-of-life Care. Approval for the study was obtained from THL Dnr: 12345556. The Finnish legislation does not mandate Ethics Committee approval for retrospective registry-based studies and separate ethical approval was not required.

2.5 | Statistical Analysis

Statistical analyses were performed using IBM SPSS Statistics, version 29 (IBM Corp., Armonk, NY, USA). Descriptive data are reported as medians with ranges or as frequencies and percentages. Patients were classified according to the timing of their first specialist palliative care contact (Group I vs. Group II). Categorical variables were compared using Pearson's chi-squared or Fisher's exact tests, while continuous variables (e.g., hospital days) were analysed with Mann-Whitney *U* tests due to non-normal distributions. Multivariable logistic regression was applied to identify factors independently associated with emergency department contacts and hospitalisations during the last month of life, adjusting for age, gender, and municipality type. Statistical significance was defined as $p < 0.05$.

3 | Results

3.1 | Patient Characteristics

Of 1199 patients who died of pancreatic cancer, 52% were female ($n = 621$). Median age at death was 74 years (range 34–101). Two-thirds of the patients (66%, $n = 793$) lived in an urban environment, with the corresponding number of patients being 17% in both semi-urban and rural municipality types. Patient characteristics are presented in more detail in Table 1.

3.2 | Timing of SPC Contact

SPC contact was established for 438 patients (36%) and median time from first contact to death was 51 days (0–662). One-fourth

TABLE 1 | Patient characteristics.

Number of patients (%)	All patients ($n = 1199$)	Group I: SPC > 30 days before death ($n = 270$)	Group II: SPC ≤ 30 days before death or no SPC ($n = 929$)	<i>p</i>
Age in years, median (range)	74 (34–101)	74 (42–99)	74 (34–101)	0.753
Gender				0.475
Male	578 (48%)	125 (46%)	453 (49%)	
Female	621 (52%)	145 (54%)	476 (51%)	
Municipality type				
Urban	793 (66%)	224 (83%)	569 (61%)	< 0.001
Semi-urban	198 (17%)	20 (7%)	178 (19%)	< 0.001
Rural	208 (17%)	26 (10%)	182 (20%)	< 0.001
ICD-10 diagnosis code Z51.5 palliative care	755 (63%)	227 (84%)	528 (57%)	< 0.001
Specialist palliative care contact	438 (36%)	270 (100%)	158 (17%)	< 0.001
Median time from first specialist palliative care contact to death	51 days (0–662 days)	89 days (31–662 days)	13 days (0–30 days)	< 0.001

Abbreviations: n = number of patients, SPC = specialist palliative care.

of the patients ($n=272$, 23%) had a SPC contact >30 days before death (Group I), whereas most of the patients did not have any contact ($n=773$, 64%), or had a contact ≤ 30 days of life ($n=154$, 13%) to SPC (Group II). The patients in Group I and II did not differ in terms of gender or median age, but SPC contact >30 days before death was more likely for patients living in urban environments ($p<0.001$) (Table 1).

The time from the first SPC contact to the patient's death varied between 0 and 663 days, with the median being 51 days. Time from first contact to death was 1 month for 13% ($n=157$), 3 months for 25% ($n=295$), and 6 months for 29% ($n=353$) of the patients.

3.3 | Healthcare Utilisation in the Last 6 and 1 Months of Life

Most of the patients with pancreatic cancer were in need of healthcare services in secondary healthcare (82%, $n=986$), primary healthcare (69%, $n=821$), and ED (91%, $n=1086$) during the last 6 months of life. The need for secondary healthcare services and ED services decreased as death approached, whereas the need for primary care services remained more stable. The corresponding percentages 1 month before death were 49% ($n=593$), 62% ($n=749$), and 59% ($n=702$), respectively. The need for social services was not common in this patient cohort.

3.4 | Association With Timely SPC Contact

Compared with Group II, patients in Group I had significantly fewer ED contacts (50% vs. 61%, $p<0.001$) and fewer hospitalisations (62% vs. 85%, $p<0.001$) in the last month of life. Similarly, readmission rates were lower in Group I, including both ED recontacts (24% vs. 31%, $p=0.030$) and secondary care readmissions (10% vs. 20%, $p<0.001$). They were also more likely to receive hospital-at-home services (44% vs. 9%, $p<0.001$) and to be admitted to SPC wards (23% vs. 5%, $p<0.001$). Utilisation details are shown in Table 2 and Figure 1.

3.5 | Factors Associated With Emergency Department Visits and Hospitalisations in Secondary Care

In a logistic regression model, patients from rural municipalities were less likely to experience ED contact and hospitalisation in secondary care during the last month of life compared with those from urban areas (OR 0.67, 95% CI 0.49–0.92). The timing of SPC contact showed a consistent association with both outcomes: patients whose first SPC contact occurred ≤ 30 days before death or who had no contact had higher odds of ED contacts (OR 1.71, 95% CI 1.30–2.27) and more than fourfold higher odds of hospitalisation in secondary care (OR 4.77, 95% CI 3.47–6.57) compared to patients with timely SPC contact (Tables 3 and 4).

3.6 | Place of Death

Hospital was the most common place of death (82%, $n=983$). Fifteen percent ($n=175$) of patients died at home, 9% ($n=103$)

in a SPC ward, and 3% ($n=41$) in a long-term facility. Earlier SPC contact was associated with a higher likelihood of home death (19% vs. 13%, $p=0.014$) and death in SPC ward (22% vs. 5%, $p<0.001$), whereas these patients had lower likelihood of hospital death (56% vs. 79%, $p<0.001$).

4 | Discussion

The present study was based on a representative population-based nationwide cohort, where all 1199 patients who deceased of pancreatic cancer in 2019 in Finland were included. There were three key observations. Firstly, patients with the first SPC contact >30 days before death used secondary healthcare services and were in need of ED services less frequently during the last month of life. Secondly, treatment in SPC near EOL and dying in SPC ward or home was more frequent for patients with earlier SPC contact. Third, access to SPC was relatively low, and we observed that there are geographical differences, as patients living in an urban environment were more likely to receive timely SPC.

In our study, only one-third (36%) of the patients with pancreatic cancer received SPC, and for 23% of the patients SPC contact took place before the last month of life. Despite the recommendations outlining the need for early integrated PC, similar findings have been reported among patients with pancreatic cancer in earlier studies. More precisely, in Finnish University Hospital cohorts, 20%–49% of the patients with pancreatic cancer have had contact with a PC unit at any time [6, 20], and in a US cohort of pancreatic cancer patients treated in a high-volume academic institution, 29% of the patients received PC, among whom 9% received early PC [29]. The care pathway should be further developed to ensure the availability of SPC and, as ESMO and ASCO state, preferably at an early stage of the disease trajectory [8, 9].

The median time from the first SPC contact to death was less than 2 months (51 days), which to our belief reflects not only the poor prognosis of these patients, but also a tradition in which systematic early integration of PC has not been established. However, similar findings have been reported with Danish pancreatic cancer patients, as median time from SPC contact to death was 35 days [30] and in a representative meta-analysis where median duration of PC from initiation to death was only 19 days [31]. Patients with slower disease course will have time to be referred to SPC and time to benefit from it even if the referral would occur only after discontinuation of oncological treatment. However, patients with more aggressive disease may not have time to reach SPC if the referral has not been made in an early disease trajectory. Among patients with pancreatic cancer, longer overall survival has been reported for patients who received SPC, when compared to those without palliative care contact [6]. Early integration should be warranted for all patients, also for those with the short prognosis.

This nationwide data showed that among patients with pancreatic cancer who had earlier PC contact, use of secondary healthcare services and emergency services was significantly less frequent during their last month of life compared with patients with late/no SPC contact. Timely SPC contact was also associated with significantly fewer readmissions, with

TABLE 2 | Utilisation of healthcare services in the final month of life according to SPC contact.

Number of patients (%)	All patients (n = 1199)	Group I: SPC > 30 days before death (n = 270)	Group II: SPC ≤ 30 days before death or no SPC (n = 929)	p
Emergency department contacts	702 (59%)	134 (50%)	568 (61%)	< 0.001
Outpatient clinic contacts				
Secondary care	633 (53%)	98 (36%)	535 (58%)	< 0.001
Primary healthcare	806 (67%)	161 (60%)	645 (69%)	0.003
Hospitalisations				
All hospitalisations	955 (80%)	167 (62%)	788 (85%)	< 0.001
Secondary care	590 (49%)	67 (25%)	523 (56%)	< 0.001
Primary healthcare	663 (55%)	121 (45%)	542 (58%)	< 0.001
Readmissions				
Emergency department recontacts	353 (29%)	65 (24%)	287 (31%)	0.030
Secondary care hospital readmission	213 (18%)	27 (10%)	186 (20%)	< 0.001
Primary care hospital readmissions	169 (14%)	29 (11%)	140 (15%)	0.072
Specialist palliative care				
Palliative care outpatient unit	137 (11%)	75 (28%)	62 (7%)	< 0.001
Hospital-at-home	201 (17%)	119 (44%)	82 (9%)	< 0.001
Specialist palliative care ward	110 (9%)	62 (23%)	48 (5%)	< 0.001
Social services	64 (5%)	10 (4%)	54 (6%)	0.175
Home care	503 (42%)	135 (50%)	368 (40%)	0.002
Place of death				
Home	175 (15%)	52 (19%)	123 (13%)	0.014
Hospital-at-home SPC	48 (4%)	30 (11%)	18 (2%)	< 0.001
Hospital	882 (74%)	151 (56%)	731 (79%)	< 0.001
Long-term care	39 (3%)	7 (3%)	32 (3%)	0.487
Specialist palliative care ward	103 (9%)	60 (22%)	43 (5%)	< 0.001

lower rates of both ED recontacts and hospital readmissions in secondary care. Earlier PC contact remained an independent factor associated with reduced intensity of EOL care even after adjusting for age, gender, and municipality type. This is in line with previous findings assessing the effect of PC on patients' EOL care [12, 14, 32]. Cancer patients have been found to benefit from early PC intervention [33, 34] and in previous studies the benefits from PC have extended beyond the use of hospital resources, as it has been shown to improve cancer patients' quality of life, to decrease the symptom burden, and to be associated with better satisfaction of care [35–38]. The diagnostics and disease-modifying treatments of pancreatic

cancer are provided in secondary healthcare in Finland, but as death approaches the care should focus on palliative care units closer to the patient's home instead. Due to the aggressive nature of pancreatic cancer, it is not rare that the diagnosis, disease-modifying oncological treatments, and their possible side effects, as well as the decision to terminate anti-cancer treatments and start palliative care, may all take place within a few months.

Patients with cancer may have both avoidable and non-avoidable reasons for ED visits during the last months of their life [39]. Indeed, nearly 60% of the patients in our study had ED contact

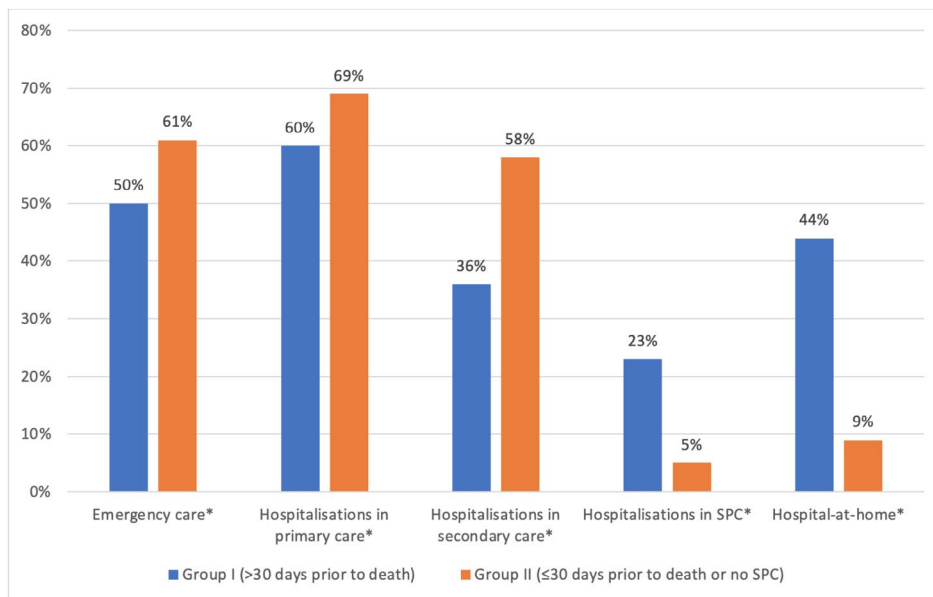


FIGURE 1 | Emergency department contacts and hospitalisations in the last month of life according to the time of first specialist palliative care (SPC) contact. * p -value < 0.001.

TABLE 3 | Factors associated with emergency department contacts during the last 30 days of life: Logistic regression analysis.

	<i>n</i>	OR	95% CI	<i>p</i>
Age at death	1199	0.990	0.979–1.002	0.090
Gender				0.057
Female	621	Reference		
Male	578	0.795	0.682–1.007	
Municipality type				< 0.001
Urban	793	Reference		
Semi-urban	198	0.776	0.562–1.071	0.123
Rural	208	0.671	0.491–0.919	0.013
Timing of specialist palliative care contact				< 0.001
Group I	270	Reference		
Group II	929	1.714	1.295–2.268	

Note: Age at death was analysed as a continuous variable. Group I = first SPC contact > 30 days before death, Group II = first SPC contact ≤ 30 days before death or no contact. Abbreviations: CI = confidence interval, *n* = number of patients, OR = odds ratio, SPC = specialist palliative care.

during the last month of their life. Bile duct obstruction and infections are typical causes for ED visits, and in addition chemotherapy can cause complications that necessitate acute care. Nevertheless, symptomatic patients with advanced cancer should receive care outside crowded EDs, and to ensure this, an advance care plan (ACP) is warranted [40]. Early palliative intervention in a SPC unit includes a discussion on the ACP and

TABLE 4 | Factors associated with hospitalisations in secondary care during the last 30 days of life: Logistic regression analysis.

	<i>n</i>	OR	95% CI	<i>p</i>
Age at death	1199	0.976	0.964–0.987	< 0.001
Gender				0.003
Female	621	Reference		
Male	578	0.688	0.539–0.878	
Municipality type				< 0.001
Urban	793	Reference		
Semi-urban	198	0.508	0.364–0.708	< 0.001
Rural	208	0.481	0.347–0.667	< 0.001
Timing of specialist palliative care contact				< 0.001
Group I	270	Reference		
Group II	929	4.774	3.468–6.574	

Note: Age at death was analysed as a continuous variable. Group I = first SPC contact > 30 days before death, Group II = first SPC contact ≤ 30 days before death or no contact. Abbreviations: CI = confidence interval, *n* = number of patients, OR = odds ratio, SPC = specialist palliative care.

this, to our belief, might be the reason behind the decrease in ED visits for the patients in Group I. Indeed, in a Finnish cancer patient population, admissions to ED tended to decrease after PC intervention [41].

Many patients with cancer would choose to die at home, and in a Swedish cancer patient cohort admitted to PC team, this was the

actual place of death for the majority (76%) of the patients [42]. However, despite this finding, patients' actual place of death often does not align with the patient's preferences and the portion of cancer patients dying at home is smaller [43]. Indeed, in the present study, even if the probability of dying at home was higher in Group I, the proportion of patients dying at home was distinctly small for both groups (19% in Group I and 13% in Group II). Instead, dying in hospital was common for both groups (56% in Group I and 79% in Group II) in the present study. During the study period, SPC at home and hospital-at-home services were not comprehensively available in Finland, which might have affected the patients' place of death. First-time SPC episodes in patients with pancreatic cancer have often been found to begin in a deteriorating phase and end up in death [44] when there is no time to arrange EOL care, and hospital might be pronounced as the place of death. For patients with earlier contact with SPC, the probability of dying in a specialist PC ward was fourfold in the present cohort.

In addition to the present study, where regional differences in the referral to PC were observed, similar findings have also been reported earlier among patients with pancreatic cancer. In a Danish nationwide study, the time from the diagnosis to referral to SPC was affected by the region of residence [30]. Also, in a US cohort, patients in small towns and rural areas had lower adjusted odds of receiving hospice care compared to patients in metropolitan areas [45]. Also in South-West Finland, the distance between the patient's domicile and hospital affected patients' care in terms of the use of radiotherapy during the last year of life [46]. PC education and PC services have been under active development in Finland during the last decade [47] but regional differences in the availability of the PC services remain, highlighting the need to continue this development. National recommendations for guiding all patients with pancreatic cancer to PC services at an early stage of the disease could partly diminish these differences.

The strength of this study was the comprehensive population-based nationwide data including all patients who died from pancreatic cancer in a period of 1 year. Nevertheless, the present study should also be interpreted in the context of its limitations. Data were available from the national registries, but neither patient-related nor caregiver-related outcomes, such as individual patients' disease trajectories, symptom burdens, or patients' wishes, could be evaluated. The timing of the SPC contact could only be assessed in relation to patients' death, whereas time from the diagnosis to the first SPC contact or integration of palliative care with oncology could not be evaluated. In addition, neither the type nor the histopathology of the pancreatic cancer could not be verified from the data and therefore its effect on the timing of SPC could not be evaluated. However, obligatory legislation provided reliable and encompassing registry-based data in which all contacts with healthcare and social care services were included.

5 | Conclusions

In conclusion, this study demonstrated that SPC > 30 days before death among patients with pancreatic cancer was associated with lower secondary healthcare utilisation, hospitalisations, and ED contacts during the last month of life. In addition,

hospital as a place of death was less likely, whereas death in a SPC ward was more likely among the patients who had earlier SPC contact. Timely SPC is warranted for all patients with pancreatic cancer to ensure the optimal use of healthcare resources near EOL and to enable patients to benefit from SPC.

Author Contributions

Outi Akrén: project administration, supervision, conceptualization, investigation, writing – review and editing. **Timo Carpén:** project administration, supervision, data curation, conceptualization, investigation, writing – review and editing, software, formal analysis. **Tiina Saarto:** conceptualization, investigation, writing – review and editing, funding acquisition, supervision. **Liisa Rautakorpi:** writing – review and editing, writing – original draft, conceptualization, investigation. **Nelli-Sofia Nähls:** writing – review and editing, software, formal analysis, conceptualization, investigation, visualization, data curation. **Mikko Nuutinen:** data curation, software, conceptualization, formal analysis.

Acknowledgements

For the assistance with statistical analyses, the authors would like to acknowledge Eliisa Löyttyniemi from the University of Turku.

Funding

The present study was funded by the Cancer Foundation Finland, Helsinki University Hospital, Comprehensive Cancer Center, State Research Funding, and Cancer Society of Southwest Finland.

Consent

The authors have nothing to report.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data are part of a dataset owned by the Finnish Institute for Health and Welfare (THL) and were used under a licence in the present study. Data are not publicly available due to Finnish legislation, but data permit can be requested from the Finnish Social and Health Data Permit Authority, Findata.

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