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ORIGINAL RESEARCH

The Utilization of Specialist Palliative Care and Other Health Care Services at the End of Life Among Patients with Head and Neck Cancer: A Nationwide Cohort Study

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ABSTRACT

Introduction: The end of life of patients with head and neck cancer (HNC) is plagued by significant morbidity and high symptom burden, emphasizing the need for palliative care. Our aim was to evaluate the utilization of health care services, including specialist palliative care (SPC), among patients with HNC at the end of life. In addition, we wanted to explore the timing of SPC contact on the utilization of health care services at the end of life.

Methods: The study population consisted of all 281 patients who died of HNC in 2019 in Finland. Data were collected from nationwide registries. Patients were divided into two groups according to the timing of their first contact with an SPC unit: early (>30 days before death), and late/no (≤30 days before death or no contact).

Results: Mean age at death was 72 years, and 66% were male. The hospital was the most common place of death (82%). Ninety-three (33%) patients had contact with an SPC unit, and the median time of the first SPC contact was 62 days before death. Comparing those with early and late/no SPC contact, the early group was significantly associated with lower secondary health care hospitalization (31% vs. 53%; $p = 0.002$) and emergency care utilization (33% vs. 52%; $p = 0.006$) during the last month of life. The early SPC group was also associated with higher utilization of home care (52% vs. 36%; $p = 0.021$), SPC outpatient clinic (24% vs. 5%; $p < 0.001$),

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SPC ward (22% vs. 4%; $p < 0.001$), and palliative hospital-at-home services (45% vs. 5%; $p < 0.001$) during the last month of life. Among patients with the early SPC contact, SPC ward was significantly more likely to be the place of death (18% vs. 4%, $p < 0.001$) compared with patients with late/no SPC contact.

Conclusion: Patients with HNC utilize health care services at high rates at the end of life. Early SPC contact is associated with increased SPC service use and decreased utilization of secondary health care and emergency care, highlighting the need for early and greater access to SPC services for patients with HNC.

Keywords: Specialist palliative care; Palliative care; End of life; Head and neck cancer; Health care utilization

Key Summary Points

Why carry out this study?

Despite aggressive treatment modalities, head and neck cancers (HNC) typically lead to significant symptom burden, morbidity, and short life expectancy.

Although there is an increasing number of studies demonstrating the benefits of early palliative care implementation, no consensus exists on the concept of appropriate palliative care among patients with HNC.

What was learned from the study?

Early specialized palliative care (SPC) contact is associated with increased SPC service use and decreased utilization of secondary health care and emergency care, highlighting the need for early and greater access to SPC services for patients with HNC.

It is of vital importance that palliative care be offered more comprehensively for patients with HNC during the whole disease trajectory.

INTRODUCTION

Head and neck cancers (HNCs) consist of malignant tumors of the larynx, oral cavity, pharynx, lips, nasal cavity, paranasal sinuses, and salivary glands. Approximately 940,000 new HNC cases were diagnosed and over 480,000 deaths reported worldwide in 2022. HNC-related deaths accounted for 4.9% of cancer deaths worldwide [1]. Approximately 970 new HNC cases were diagnosed in 2022 in Finland [2].

At the time of HNC diagnosis, over 60% of patients already have locally advanced cancer [3, 4]. Unfortunately, more than 65% of HNC cases develop recurrent or metastatic disease, typically 12–18 months after completion of curative treatment intent [5, 6]. Patients with non-curable disease and those with recurrent HNC carry a poor prognosis, and their median overall survival time is approximately 6 months [7, 8]. However, novel immunotherapies have prolonged the overall survival time somewhat [9, 10]. The differences between men and women in the incidence of different subtypes of HNC vary substantially according to the exact localization of the cancer along the aerodigestive tract, patient age, and whether the patient smokes or drinks alcohol, as has been presented in the study by Park et al. (2022) [11]. There is also a wide global disparity in the risk of developing different subtypes of HNC between men and women [12].

Despite aggressive treatment modalities, HNCs typically lead to significant symptom burden, morbidity, and short life expectancy, and patients may have challenging comorbidities and psychosocial needs [13]. Symptoms related to HNC are broad and challenging, such as complex pain, airway obstruction, and debilitating effects on the ability to communicate [13–20], emphasizing the need for palliative care throughout the disease trajectory. Palliative care decision, with a focus on symptom control and quality of life without curative or disease-modifying treatment intent, is made by only 5–14% of newly diagnosed patients with HNC [21–24]. A palliative care decision is typically made when the disease is determined to be incurable, at a remarkably advanced stage, by the patient's preference, due to frail overall condition or compliance issues. HNCs are manifested in functionally and anatomically critical regions correlating with unique and varying challenges in treatment and major disease symptom burden. Treatment decisions and modalities, such as late surgical procedures, leading to prolonged hospitalization, complications, and increased morbidity should therefore be avoided [17, 25–27].

The utilization of palliative care services among patients with HNC has not been sufficiently studied, and no population-based studies exist. There is a need to systemically compile information on care of patients with HNC in end-of-life circumstances for the future development of specialist palliative care (SPC) practices, since no worldwide consensus exists on organized palliative care in this patient population [17]. In this nationwide study, we aimed to evaluate the utilization rate of services in health care, social care, and specialist palliative care among patients with HNC at the end of life. In addition, our aim was to investigate potential differences in health care service usage in association with the timing of first contact with SPC units. Further, the aim was to determine if the utilization of non-palliative hospital-based health care services decreases when a palliative service contact is established.

METHODS

Study Cohort

The present study cohort consisted of all ($n = 281$) patients whose cause of death was registered as HNC in Finland in 2019. The cohort was formed from nationwide data of the Causes of Death Register (Statistics Finland, 2019). The International Classification of Diseases, Tenth Revision (ICD-10) coding for head and neck cancers (C00-C14, C30-C32) was applied. Demographic data collected included sex, age at death, place of death, municipality (defined by Statistics Finland), and the university hospital catchment area where the patient was managed.

Data Collection and Determination of Health Care and Social Services

Data were collected from the Finnish Kanta services and the National Care Registers. Finnish law requires all health care providers to contribute to these systems. The Kanta Service is a digital platform whose data include both social services and health care.

The Finnish health care system is tax-funded and consists of a highly decentralized three-level organization and a much smaller private sector. HNC management is centralized to the five university hospitals. Information on utilization of primary, secondary, and tertiary care (including SPC unit wards and outpatient units), utilization of social services and home care, visits and care periods at SPC units, and contacts with the emergency departments were collected from January 1, 2018, to December 31, 2019. All the data from registries were pseudonymized using research numbers instead of personal identification numbers. The collected data were linked to a health service unit code list.

Each of the patients with HNC who died in 2019 was treated in one of the six catchment areas, these being the autonomic region of Åland or one of the five Finnish university hospitals: Helsinki University Hospital (HUS), Tampere University Hospital (TAYS), Turku University Hospital (TYKS), Kuopio University Hospital (KUH), and Oulu University Hospital (OYS). Tertiary care data were collected from the five university hospitals, and secondary care statistics were collected from 20 secondary hospitals working in coordination with the university hospitals. Primary care data were collected from municipal primary care units that worked in cooperation with secondary and tertiary care hospitals. In this study, tertiary and secondary care data are collectively referred to as secondary health care data.

Definition of Specialist Palliative Care Services

At the time of the study, palliative care services in Finland were publicly provided at both general and specialized levels. General level services are provided in certain primary and secondary hospitals, primary health care, home care, and social service units that care for dying patients. SPC is provided by specialized multidisciplinary teams in primary and secondary health care, including palliative outpatient clinics or wards, palliative consultation services, hospices, and palliative hospital-at-home units. Data considering hospice units were included in the SPC ward data in this study. The regional palliative care pathway is coordinated by the palliative care center of the university hospital of the area. In this study, if patients died at home with support of palliative hospital-at-home service during the last 3 days before death, they were considered to have had home death with support of specialized palliative care.

When a palliative care decision is made, i.e. termination of curative-intended or life-prolonging anticancer treatments and instead focusing on palliative care, an ICD-10 diagnosis code Z51.5 is registered in the patient records. However, in 2019, the use of Z51.5 was not systematic in Finland. Palliative radiotherapy (short radiation treatment periods and low doses) can be given also after palliative care decision is made solely with the purpose of alleviating symptoms.

Every contact with an SPC unit (whether an SPC ward, outpatient clinic, or SPC hospital-at-home) was counted as a separate contact. Patients were divided into two groups according to the timing of the first SPC unit contact as follows: (1) early SPC contact group, i.e. contact > 30 days prior to death, and (2) late/no SPC contact group, i.e. contact ≤ 30 days prior to death or no contact.

Ethical Statement

The study was performed in collaboration with the Finnish Institute for Health and Welfare (THL) as part of the Quality Information on Palliative Care and End-of-life Care Project. The study was approved by THL (Dnr: 12345556). No separate ethics committee approval was needed for this registry-based study according to Finnish Law.

Statistical analysis

Statistical analyses were performed using IBM -SPSS version 29 software (IBM Corp., Armonk, NY, USA). Descriptive statistics were reported as means with standard deviations (SD) and medians with ranges. Pearson's chi-squared test was used to compare categorical variables. A p-value of < 0.05 was considered as statistically significant.

RESULTS

Demographic Statistics

The study group consisted of 281 patients with HNC, of whom 185 (65.8%) were male and 96 (34.2%) were female. Mean age at death was 72 years (SD 12.3). Cancers of the lip and the oral cavity were the most frequently occurring cancers ($n = 107$, 38.1%). Demographic factors are presented in Table 1.

Utilization of Health Care Services During the Last 6 Months of Life

Patients with HNC were shown to use secondary (97.5% of all patients) and primary health care (94.5%) services abundantly during the last 6 months prior to death. A considerable portion, 84% of all patients, utilized emergency services, and approximately 56% of all patients had contact with home care during the 6 months prior to death. The percentage of all patients utilizing secondary (78.6%) and primary health care (78.6%) remained high during the last month prior to death. The reliance on emergency services also remained very high, 47% of all patients, in the last month prior to death. Social service usage was altogether low among all patients. Health care service utilization is presented in Fig. 1.

Table 1 Demographic information

Demographic information	
Total (%)	*n* = 281 (100)
Mean age at death, years (SD)	72.4 (12.3)
Sex, *n* (%)	
Male	185 (65.8)
Female	96 (34.2)
Municipality, *n* (%)	
Urban	191 (68.0)
Semi-urban	49 (17.4)
Rural	41 (14.6)
Site of cancer, *n* (%)	
Lip or oral cavity	107 (38.1)
Pharynx	94 (33.5)
Larynx	38 (13.5)
Nasal cavity or paranasal sinuses	25 (8.9)
Major salivary glands	17 (6.0)
ICD-10 diagnosis Z51.5 registered, *n* (%)	153 (54.4)
Specialist palliative care unit contact, *n* (%)	93 (33.1)
Median time in days of the first SPC unit contact to death, (range)	62 (0–558)

SPC specialist palliative care, *SD* standard deviation

Utilization of SPC Services

In total, 93 patients (33.1%) had a contact with an SPC unit. The timing of the first SPC contact is presented in Fig. 2. The median time in days of the first SPC unit contact prior to death was 62 days (range 0–558, SD 131). In total, 153 patients (54.4% of all patients) had a palliative care diagnosis code Z51.5 (ICD-10) registered on their patient record. Of the 153 patients, 60 patients (39.2%) did not have any contact with an SPC unit. Among all patients with an SPC contact (93 patients), the mean number of contacts was 4 (IQR = 9).

Early SPC contact (≥ 31 days prior to death) was present in 67 patients (23.8%) and late/no contact (≤ 30 days/no contact) in 214 patients (76.2%). Of the 214 patients, 26 (28.0% of all patients with an SPC unit contact) had their first SPC unit contact during the last month before death and 188 patients had no SPC unit contact.

Patients in the group of early SPC contact had more often established a contact with a palliative hospital-at-home (44.8% vs. 5.1%, $p < 0.001$), were more likely to be hospitalized in SPC wards (22.4% vs. 3.7%, $p < 0.001$), and were more likely to have utilized an SPC outpatient clinic (23.9% vs. 5.1%, $p < 0.001$) during the last month before death than patients with late/no SPC contact (Table 2).

Utilization of Health Care and Social Services During the Last Month of Life

Secondary and primary health care, emergency department (ED), social services, and home care utilization rates are shown in Table 3. The study population utilized both secondary and primary care services heavily during the last month prior to death, as shown in Fig. 1. Patients with late/no SPC contact had significantly more secondary health care hospitalization periods than the patients with early SPC contact (52.8% vs. 31.3%, $p = 0.002$). There was, however, no meaningful difference in secondary care contacts between the late/no SPC group and the early SPC group. Late/no SPC contact was also associated with more ED utilization compared to patients with early SPC contact (32.8% vs. 51.9%, $p = 0.006$). Of all patients, 40.2% had a contact with home care services during the last month, with early SPC contact increasing the utilization rate compared with late/no SPC contact (52.2% vs. 36.4%, $p = 0.021$). The utilization of social services was low in the whole population, 8.9% of all patients, and no association with the timing of SPC contact was found.

Place of Death

The majority of all patients, 231 (81.9%), died in a hospital, including SPC wards. Table 4 presents statistics concerning place of death. Patients with an early SPC contact were

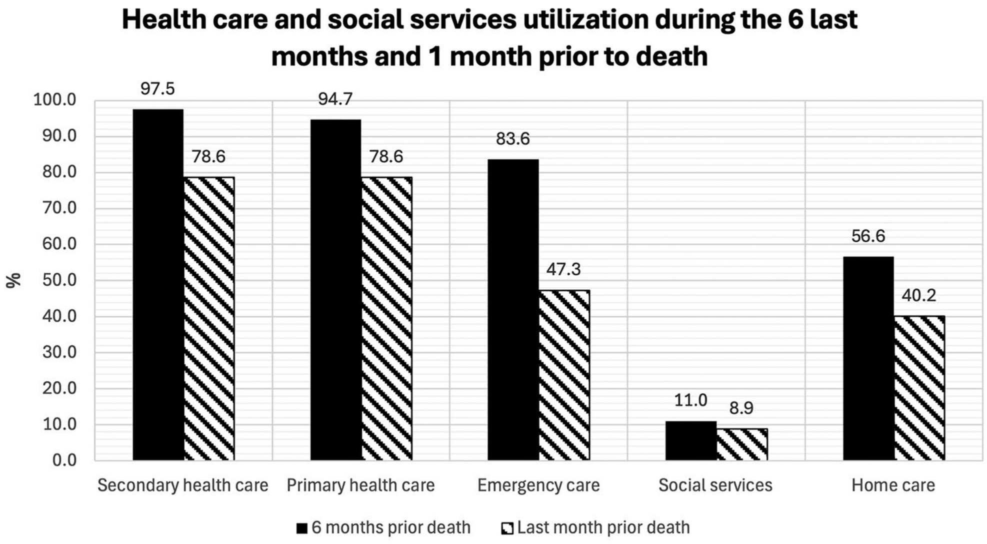

Fig. 1 Utilization of health care services during the last 6 months and last month prior to death among the whole study population

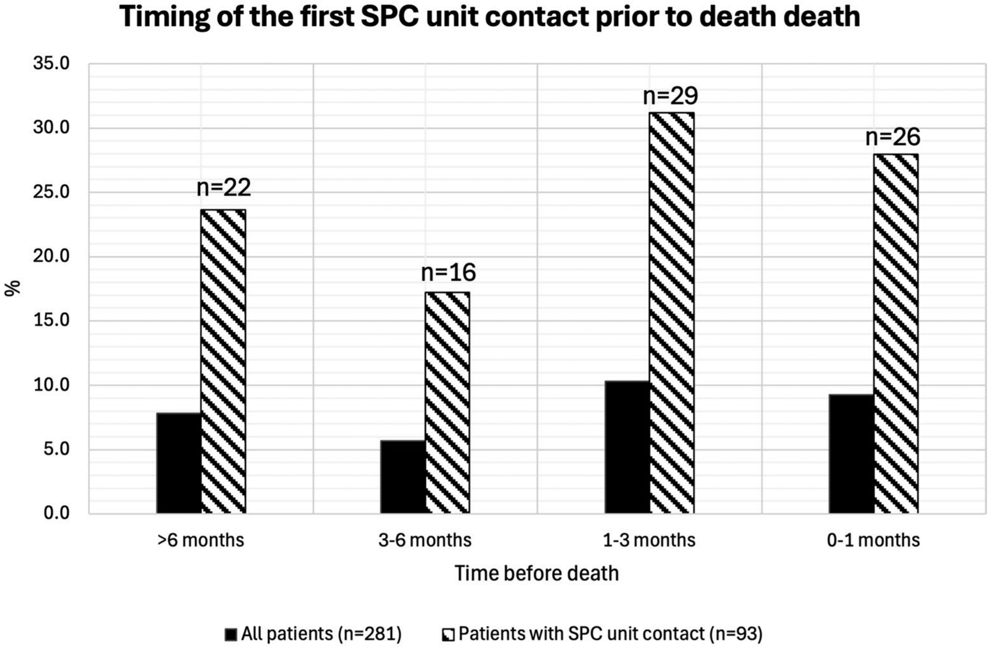

Fig. 2 Timing of the first specialist palliative care (SPC) unit contact prior to death

significantly more likely to die in an SPC ward than patients with late/no SPC contact (17.9% vs. 3.7%, $p < 0.001$). Nine patients (3.2%) died at home with support of hospital-at-home service.

DISCUSSION

This nationwide study showed that patients with HNC and early SPC contact had significantly

Table 2 The utilization of specialist palliative care services during the last month of life

	All patients, *n* (%)	Early SPC (%)	Late/no SPC (%)	*p*-value
Total (%)	281 (100)	67 (100)	214 (100)	
SPC hospital-at-home service	41 (14.6)	30 (44.8)	11 (5.1)	**< 0.001**
SPC ward	23 (8.2)	15 (22.4)	8 (3.7)	**< 0.001**
SPC outpatient clinic contacts	27 (9.6)	16 (23.9)	11 (5.1)	**< 0.001**

SPC specialist palliative care

p-values < 0.05 are bolded

Table 3 Health care services utilized during the last month prior to death

	Total (%)	Early SPC (%)	Late/no SPC (%)	*p*-value
Total (%)	281 (100)	67 (100)	214 (100)	
Secondary health care contacts	221 (78.6)	52 (77.6)	169 (79.0)	0.813
Primary health care contacts	221 (78.6)	50 (74.6)	171 (79.9)	0.357
Secondary health care hospitalization	134 (47.7)	21 (31.3)	113 (52.8)	**0.002**
Primary health care hospitalization	140 (49.8)	28 (41.8)	112 (52.3)	0.132
Emergency department contacts	133 (47.3)	22 (32.8)	111 (51.9)	**0.006**
Social services	25 (8.9)	8 (11.9)	17 (7.9)	0.316
Home care	113 (40.2)	35 (52.2)	78 (36.4)	**0.021**

SPC specialist palliative care

p-values < 0.05 are bolded

Table 4 Association between the timing of the first specialist palliative care (SPC) contact and place of death

	Total (%)	Early SPC (%)	Late/no SPC (%)	*p*-value
Total (%)	281 (100)	67 (100)	214 (100)	
Place of death				0.402
Home	36 (12.8)	11 (16.4)	25 (11.7)	0.311
Support of SPC hospital at home	9 (3.2)	N/A*	N/A*	
Hospital	230 (81.9)	54 (80.6)	176 (82.2)	0.760
SPC ward	20 (7.1)	12 (17.9)	8 (3.7)	**< 0.001**
Long-term care facility	15 (5.3)	N/A*	N/A*	

SPC specialist palliative care, *N/A* not applicable

*Results with number of patients less than 5 are not presented due to established patients' privacy rights.

p-values < 0.05 are bolded

lower secondary health care and emergency care utilization at the end of life than those with late/no SPC contact. In addition, patients with early SPC contact had significantly higher utilization of palliative care services. To our knowledge, this is the first study to show the nationwide benefits from early SPC on end-of-life health care utilization among patients with HNC. However, only one third of our patient population received SPC services before death.

The end of life of patients with HNC is plagued by significant morbidity and high symptom burden, emphasizing the need for palliative care [13–20]. An American national study by Civantos et al. in 2021 noted that only 22.5% of patients with advanced-stage HNC received palliative care, which is notably less than among our study population [28]. In addition, a previous study conducted in Finland by Haltia et al. showed that 37% of all deceased patients with cancer treated at a tertiary cancer center had an SPC contact prior to death. According to the same study, approximately 45% of patients with HNC had an SPC unit visit prior to death. [29] The inclusion criteria in our study are broader, as patients not treated at the oncology departments were included, and this impacts the overall SPC unit utilization compared with the study by Haltia et al. [29]. Therefore, the probability of being in contact with an SPC unit before death seems to be higher among patients with HNC treated in tertiary centers when compared with those in a nationwide population. The study results also align with a previous scoping review study where patients with HNC were reported to be more likely to have established SPC contact prior to death compared with other cancer groups [30]. The percentage of patients utilizing palliative care services is still undeniably low considering the symptom burden at the end of life. There is a need for prospective randomized studies concerning patients with HNC as no randomized controlled studies exist on this population and the factors affecting the utilization of SPC services.

The first SPC contact occurred before the last month of life in approximately 70% of the patients with an SPC unit contact (24% of all patients). The median time was 62 days before death among all patients. The timing of first SPC contact was similar to that of the previously mentioned Finnish study [29]. However, 26 patients, approximately one third of all patients with SPC contact, had their first SPC contact only during the last month prior to death, which is considerably late in the disease trajectory. With such a limited number of patients in the late group, the credibility of comparison between patients with early and those with late SPC contact will suffer dramatically and lose its statistical power to make proper analyses. Mayland et al. concluded in a scoping review that access and timing of palliative intervention among patients with HNC varies, although the need for palliative care has been shown to be substantial [30]. Patients with HNC and recurrent or non-curable disease have a short survival time, approximately 6 months [7, 8]. Thus, the HNC-related palliative care phase is relatively short and emphasizes the importance of early and timely palliative care contact establishment. The American Society of Clinical Oncology (ASCO) has recommended implementing interdisciplinary specialized palliative care during earlier treatment phases of patients with advanced cancer and unaddressed physical, psychosocial, or spiritual distress [31].

In our study, the use of health care services was extremely high among patients who died of HNC. The total number of patients utilizing secondary health care or visiting an emergency department even during the last month prior to death was high in the study population. The results align with a previous scoping review about patients with HNC placing a high burden on health care as frequent hospitalizations and emergency care visits occur even in the last month prior to death [30]. Patients with HNC as a group have been shown to place a major burden on the health care system, typically due to a difficult symptom burden and a risk of severe complications, including risk of compromised airway [32].

Early SPC contact was associated with significantly fewer patients hospitalized in secondary health care and emergency departments during the last month before death. It can be presumed that the group with early SPC contact had better-established end-of-life care with regard to fewer patients with secondary health care treatment periods. The results are in line with the studies by Temel et al. and Scibetta et al. reporting that early implemented PC leads to reduced burdens on secondary health care [33, 34].

Compared with the late/no SPC contact group, patients with early SPC contact utilized significantly more SPC services, including SPC outpatient clinic, SPC hospital-at-home, and SPC ward services, during the last month prior to death. The low SPC hospital-at-home utilization may at least partly explain the high rates of emergency service use and hospitalizations at the end of life and the high rate of hospital deaths. The patients in the early SPC group nevertheless had more palliative hospital-at-home service and lower emergency service utilization than the patients in the late/no SPC group.

Kamisetty et al. have shown that patients with HNC die at a hospice unit more often than other cancer patient groups [35]. In our study, the place of death was the hospital in most cases and in both early SPC and late/no SPC groups. Espeli et al. (2022) had a similar finding that the majority of patients with HNC die in hospital with or without palliative intervention [36]. In our study, patients with early SPC contact were more likely to die in an SPC ward (18%) compared with the patients in the late/no SPC contact group (4%). The low percentage of deaths in the SPC unit can be attributed to lack of dedicated SPC wards and palliative hospital-at-home services in various areas of Finland at the time of our study. Only 3% of all patients died at home with the support of SPC hospital at home. Fullarton et al. concluded that the choice of patients with HNC with regard to place of death can be difficult to ensure due to the frequent need for surgical interventions that are routinely available only in certain health care facilities [37].

Although an increasing number of studies are demonstrating the benefits of early palliative care implementation, no consensus exists on the concept of appropriate palliative care of patients with HNC. Schenker et al. previously concluded that it is necessary to be more certain about the conception of a reasonable implementation of palliative care in the treatment process of HNC [17]. Temel et al. reported that palliative care is more effective if the needs of different patient subgroups are understood and care is targeted [38], which is especially important among the varying disease outcomes of HNC. To our knowledge, this is the first study to present an association between early SPC contact and increased utilization of both hospital-at-home and SPC ward services among patients with HNC.

The present study data are comprehensive and population-based, as they were collected from every catchment area in Finland. The Finnish Kanta services and the National Care Registers are well-established data sources used regionally in Finland and the treatment statistics are reliable. The retrospective design of the study is a limitation. Patient records were unobtainable due to the nature of the data and rights granted by the authorities. The differences in health care utilization between male and female patients with HNC or differences between different races or ethnicity were not incorporated in our study but provide an interesting and important area of study in the future. Timing and other information about cancer treatments, symptoms, quality of life, and comorbidities were unavailable. The cause of death is specified only by the primary cause of death, which is HNC among the population of the study.

CONCLUSIONS

This study provides a unique overview of the availability of SPC services among Finnish patients with HNC and utilization of other health care services. In this study population, only one third of the patients had contact with a specialist palliative care unit before death. Early SPC contact was associated with a lower likelihood of secondary health care treatment periods and emergency care utilization compared with patients with late/no SPC contact. Patients with early SPC contact utilized more SPC services and were more likely to be able to die in an SPC ward. It is of essential value to further evaluate the differences between treatment methods and timing of treatment interventions in correlation with palliative care contacts and time of death. Therefore, it is of vital importance that palliative care be offered more comprehensively among all patients with HNC during the whole disease trajectory.

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Data Availability. The data that support the findings of this study are available from Finnish Institute for Health and Welfare but restrictions apply to the availability of these data, which were used under license for the current study, and so are not publicly available. Data permits can be requested from the Finnish Social and Health Data Permit Authority, Findata (info@findata.fi).

Declarations

Conflict of Interest. Martti Merikari, Outi Akrén, Mikko Nuutinen, Antti Mäkitie, Tiina Saarto and Timo Carpén declare they have nothing to disclose.

Ethical Approval. The study was performed in collaboration with the Finnish Institute for Health and Welfare (THL) as part of the Quality Information on Palliative Care and End-of-life Care Project. The study was approved by THL (Dnr: 12345556). No separate ethics committee approval was needed for this registry-based study according to Finnish Law.

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