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Specialist Palliative Care and the Use of Healthcare Services Among Patients With Multiple Myeloma: A Nationwide Cohort Study

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ABSTRACT

Objectives: To investigate the access to specialist palliative care (SPC) and its impact on healthcare utilization at the end of life in patients with multiple myeloma (MM).

Methods: This retrospective cohort study examined all Finnish patients who died of MM in 2019. Data were collected from national health databases. Patients were categorized by whether they had contact with SPC or not.

Results: We identified 278 patients (median age at death 77.5 years, 44.2% male), of whom 23.4% had SPC contact a median of 38 days before death. During the last 6 months of life, 92.4% of all patients had contact with the emergency department, 83.5% were hospitalized in secondary care, and 65.5% were hospitalized in primary care hospitals. Patients with SPC contact had fewer emergency department visits (50.8% vs. 65.3%, $p = 0.041$) and hospitalizations in secondary care (41.5% vs. 62.0%, $p = 0.004$) in the last month of life and fewer hospital deaths (69.2% vs. 84.0%, $p = 0.012$).

Conclusions: Despite high healthcare service utilization at the end of life, access to SPC was often limited and late. Contact with SPC reduced acute healthcare utilization at the end of life, indicating better end-of-life care.

1 | Introduction

Multiple myeloma (MM), a clonal plasma cell malignancy, remains incurable even after the development of new effective treatments [1–5]. Globally, MM accounts for approximately 1% of all cancers and 10% of hematologic cancers [1, 6–8]. The incidence of MM increases strongly with age and is highest in the United States, Western Europe, and Australia [1, 2, 6]. In Finland, the current median age at diagnosis for patients with MM is 70 years, and the age-standardized incidence rate is 2.5–3 per 100 000 people and increasing [3, 8].

MM is characterized by malignant plasma cell proliferation in bone marrow, leading to multiple symptoms including organ

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Abbreviations: ICD-10, International Classification of Diseases, version 10; MM, multiple myeloma; SPC, specialist palliative care; THL, The Finnish Institute for Health and Welfare.

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damage such as bone lesions and fractures, anemia, hypercalcemia, and renal dysfunction [6, 8, 9]. Previous studies have shown that patients with MM suffer from numerous symptoms throughout the course of their illness. This symptom burden, typically including pain, fatigue, and dyspnea, intensifies toward the end of life, making high-quality end-of-life care crucial for these patients [9–12]. Commonly, patients with MM experience many emergency department visits and hospital admissions and often receive aggressive care at the end of life [10–13].

High-quality end-of-life care should include the involvement of palliative care services. Palliative care is the active and comprehensive care of a patient with a life-threatening illness, aiming to reduce symptom burden and to improve quality of life [14]. Patients with hematological malignancies have been described as having less frequent access to palliative care than patients with solid tumors, despite their similar or even higher symptom burden [12, 13, 15–17]. Among patients with MM, referrals to palliative care are often unsystematic and tend to occur late [12, 13, 18]. However, palliative care provided earlier for patients with MM has been shown to improve patients' quality of life and symptom management [4, 9]. Furthermore, earlier access to palliative care has been shown to decrease the use of aggressive care and secondary care hospitalizations at the end of life in patients with MM as well as in other cancers [4, 19–22].

The last month of life is widely recognized as the most intensive period of healthcare utilization, during which patients with cancer face an increased risk of emergency department visits and hospitalizations [23]. Recent studies have shown that the initiation of palliative care before the last month of life significantly reduces the likelihood of inappropriate end-of-life care among patients with cancer [22, 24].

However, data on access to palliative care services and the association of palliative care services with healthcare utilization at the end of life remain limited among patients with MM, and no nationwide data exist. Thus, the aim of this nationwide retrospective cohort study was to investigate healthcare utilization during the last 6 months of life and the place of death in connection with specialist palliative care (SPC) contact among patients with MM.

2 | Materials and Methods

2.1 | Study Cohort

This nationwide retrospective cohort study covered all adult patients ($n = 278$) who died of MM in Finland in 2019. These patients were identified from the National Causes of Death register (Statistics Finland) [25] using the International Classification of Diseases version 10 (ICD-10) codes for MM, plasma cell leukemia, and extramedullary plasmacytoma (C90.0, C90.1, and C90.2, respectively).

2.2 | Data on Healthcare and Social Services

We included sex, age at death, place of death, and municipality as demographic variables, and these data were collected from the Causes of Death Register [25]. The municipality was further defined as urban, semi-urban, or rural according to the Statistics Finland statistical grouping of municipalities [26]. The place of death was further categorized as home, long-term care facility, hospital, or SPC inpatient unit. The data collection has been described in greater detail in an earlier publication [27].

The use of healthcare services (outpatient clinic contacts, primary or secondary care hospitalizations, emergency department contacts, and SPC contacts), the use of social services, and sociodemographic data were collected from the national Care Register for Healthcare and Kanta services. In Finland, these two comprehensive databases are mandated by law to be used by all healthcare providers to capture all contacts with health care [28, 29]. We used the databases to collect data on the use of healthcare and social services during the last month and the last 6 months of life. This data included the number of emergency department contacts, hospitalizations in secondary or primary care, inpatient days, and readmissions to secondary and primary care and the use of social services and home care.

In Finland, primary healthcare is delivered through municipal health centers, whereas secondary care is provided by 20 district hospitals and tertiary care at 5 university hospitals. For the purposes of this study, secondary and tertiary care are combined and collectively referred to as secondary care.

2.3 | Palliative Care Services and Contacts

In Finland, palliative care services are provided at both primary and secondary care levels, and they are divided into general and specialist (SPC) levels. These SPC services include outpatient clinics and inpatient units (including hospice), inpatient consultative palliative care teams, and hospital-at-home services (specialized hospital-level home care). In this study, we defined all of them as a single group of SPC services.

First, we evaluated the use of healthcare and social services among all patients with MM. Second, to assess the effect of SPC on healthcare utilization, the patients were divided into two groups: patients who had contact with SPC services before death and patients who did not have any SPC contact. Furthermore, to assess the association of the timing of SPC with healthcare utilization during the last month of life, the patients were divided into three groups: (1) patients who had their first SPC contact > 30 days before death, (2) patients who had their first SPC contact ≤ 30 days before death, and (3) patients without SPC contact before death.

2.4 | Ethical Statement

This study was performed in collaboration with the Finnish Institute for Health and Welfare (THL) as a part of the project on quality information on palliative care and end-of-life care. Approval for the study was obtained from THL (THL/908/6.02.00/2021). According to Finnish legislation, separate ethical approval was not required, as the data used in the study consisted of data from deceased patients. This study was conducted according to national laws and regulations and the Declaration of Helsinki.

2.5 | Statistical Analyses

Statistical analyses were performed using SPSS, version 29 (IBM Statistics, SPSS Inc., NY, USA). Descriptive statistics are reported using medians, interquartile ranges, numbers of incidences, and percentages. Pearson's chi-square test with Fisher's exact test was used to compare categorical variables, and the Mann–Whitney *U*-test was used for continuous variables due to non-normality of distribution. $p < 0.05$ was considered statistically significant for all analyses.

3 | Results

3.1 | Patient Characteristics

Altogether, 278 patients died of MM in Finland in 2019. The patient characteristics at the time of death are presented in Table 1. The median age at death was 77.5 years, and 44.2% of the patients were male. Of all patients, only 23.4% ($n = 65$) had contact with SPC services before death. Among all patients, the median time from the first SPC contact to death was 38 days (range: 0–681 days). For patients whose first SPC contact occurred more than 30 days before death, the median was 122 days (range: 32–681 days), and for those patients whose first contact occurred during the last month, the median time was 8 days (range: 0–30 days) before death.

Figure 1 illustrates the timing of the first SPC contact. In 38.5% ($n = 25$) of patients, SPC contact started within the last month of life.

Those patients who received SPC services lived mostly in urban areas (84.6%) when compared with those who did not receive SPC (58.2%), $p < 0.001$. Palliative care ICD-10 diagnosis code Z51.5 was registered in 32.4% of all patients' medical records (Table 1).

3.2 | Place of Death

The majority of patients with MM (80.6%) died in the hospital. Among those patients with MM who had SPC contact, hospital deaths were less frequent (69.2%) when compared with those patients without SPC contact (84%, $p = 0.012$). In the SPC contact group, 24.6% of patients died in an SPC inpatient unit. Home deaths were relatively uncommon in the total cohort (7.6%) (Table 1).

3.3 | Use of Healthcare Services

The use of healthcare and social services among all patients with MM during the last 6 months of life is shown in Figure 2.

TABLE 1 | Patient characteristics in all patients and in patients with and without specialist palliative care (SPC) contact.

	All patients	Patients with SPC contact	Patients without SPC contact	*p* for difference
Number of patients, *n* (%)	278	65 (23.4)	213 (76.6)	
Age at death in years, median (range)	77.5 (43–94)	75.0 (43–93)	78.0 (49–94)	0.479
Sex, *n* (%)				0.776
Male	123 (44.2)	30 (46.2)	93 (43.7)	
Female	155 (55.8)	35 (53.8)	120 (56.3)	
Municipality type,[a] *n* (%)				
Urban	179 (64.4)	55 (84.6)	124 (58.2)	< 0.001
Semi-urban	48 (17.3)	5 (7.7)	43 (20.2)	0.023
Rural	51 (18.3)	5 (7.7)	46 (21.6)	0.010
ICD-10 code Z51.5 stated, *n* (%)	90 (32.4)	43 (66.2)	47 (22.1)	< 0.001
Place of death, *n* (%)				
Home	21 (7.6)	2 (3.1)	19 (8.9)	0.178
Hospital	224 (80.6)	45 (69.2)	179 (84.0)	0.012
SPC inpatient unit	16 (5.8)	16 (24.6)	0	n.a
Long term care facility	17 (6.1)	2 (3.1)	15 (7.0)	0.376

[a] Municipality types are classified according to number of population living in the urban settlements and the size of the largest city in the area (statistical grouping of municipalities 2024, Statistics Finland).

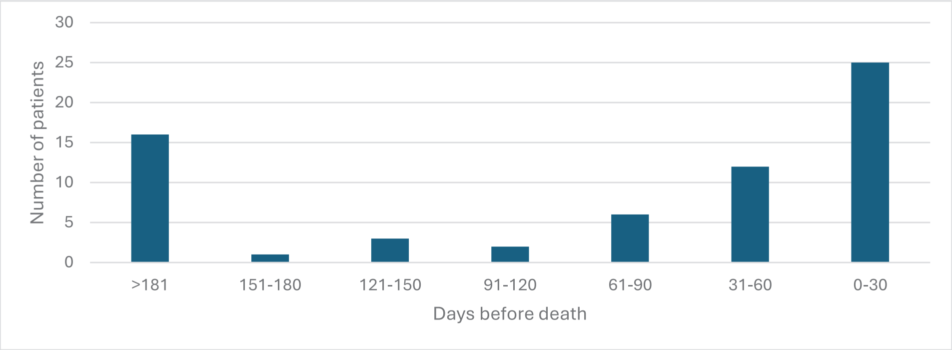

FIGURE 1 | Timing of the first SPC contact in relation to death, with the number of patients in each time category ($n=65$).

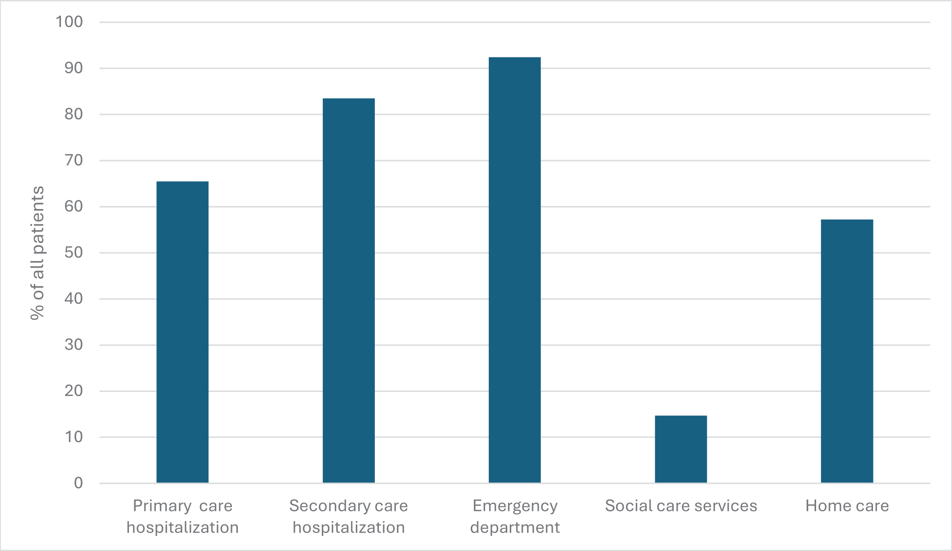

FIGURE 2 | The proportion of patients using healthcare and social services during the last 6 months of life.

Of all patients, 92.4% had contact with an emergency department; 83.5% were hospitalized in secondary care hospitals; and 65.5% in primary care hospitals.

3.4 | The Association Between SPC Services and Healthcare Service Utilization

Table 2 presents the use of healthcare services during the last month of life among patients with MM, with or without SPC contact.

A significantly lower proportion of patients in the SPC contact group had emergency department contacts during the last month of life compared with those without SPC contact (50.8% vs. 65.3%; $p=0.041$). In addition, fewer patients in the SPC contact group required hospitalization in secondary care hospitals (41.5% vs. 62.0%; $p=0.004$).

The median number of inpatient days in secondary care was 5 days among patients with SPC contact and 9 days among patients without SPC contact ($p=0.062$). No difference in primary care hospitalizations was seen between the groups (56.9% vs. 53.5%, $p=0.671$).

The use of healthcare services in the last month of life, according to the timing of the first SPC contact, is presented in Figure 3, where patients were divided into three groups: patients with early (> 30 days before death) SPC contact ($n=40$), patients with late (0–30 days before death) SPC contact ($n=25$), and patients without any SPC contact before death ($n=213$). A lower proportion of those patients with MM who had early SPC contact were hospitalized in secondary care ($p<0.001$) or had contacts with an emergency department ($p=0.049$) compared with those patients with MM who did not receive palliative care. Instead, no differences were observed in primary care hospitalizations. No differences in healthcare utilization during the last month of life were observed between those patients whose first SPC contact occurred during their last month of life and those without SPC contact (secondary care hospitalizations: 56% vs. 62%, $p=0.665$; primary care hospitalizations: 64% vs. 54%, $p=0.398$; emergency department contacts: 56% vs. 65%, $p=0.383$).

4 | Discussion

This nationwide register-based study demonstrated that despite high healthcare utilization at the end of life, especially during the

TABLE 2 | The use of healthcare and social services during the last month of life among patients with and without specialist palliative care (SPC) contact.

	All patients	Patients with SPC contact	Patients without SPC contact	*p* for difference
Number of patients	278	65	213	
Patients with emergency department contact, *n* (%)	172 (61.9)	33 (50.8)	139 (65.3)	0.041
Hospitalizations in secondary care				
Patients hospitalized, *n* (%)	159 (57.2)	27 (41.5)	132 (62.0)	0.004
Number of inpatient days, median (range)	8.0 (1–30)	5.0 (1–22)	9.0 (1–30)	0.062
Patients with readmission, *n* (%)	57 (20.5)	12 (18.5)	45 (21.1)	0.727
Hospitalizations in primary care				
Patients hospitalized, *n* (%)	151 (54.3)	37 (56.9)	114 (53.5)	0.671
Number of inpatient days, median (range)	10.0 (1–30)	11.0 (1–30)	9.00 (1–30)	0.874
Patients with readmission, *n* (%)	37 (13.3)	8 (12.3)	29 (13.6)	1.000
Other services				
Social services, *n* (%)	32 (11.5)	9 (13.8)	23 (10.8)	0.509
Home care, *n* (%)	108 (38.8)	24 (36.9)	84 (39.4)	0.772

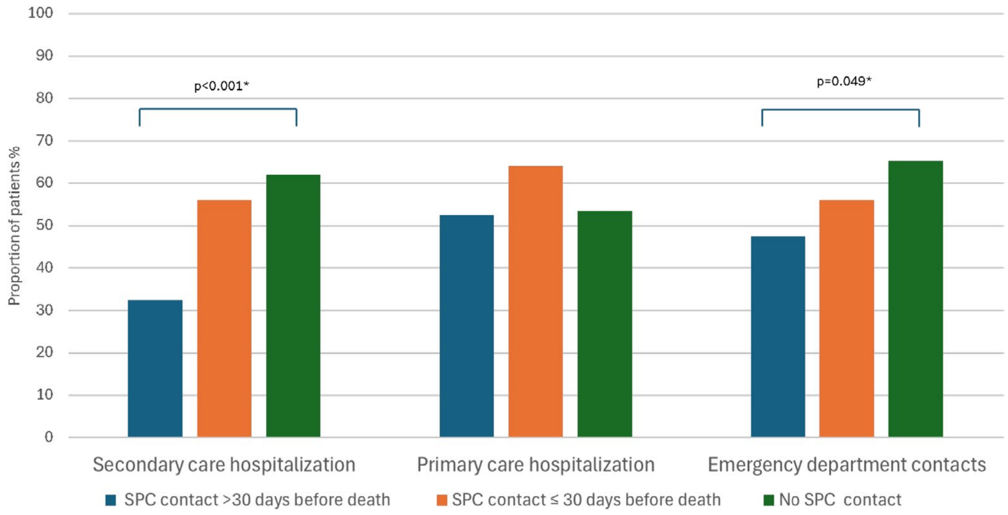

FIGURE 3 | The comparison of healthcare service use during the last month of life in patients with first SPC contact >30 days before death ($n=40$), ≤ 30 days before death ($n=25$), and patients without SPC contact ($n=213$). *Comparison of patients without access to SPC and those with first SPC contact more than 30 days before death. Only significant *p* values in comparisons are shown.

last month before death, access to SPC services among patients with MM was limited and occurred late in the illness trajectory. The median time to first SPC contact was 5 weeks before death, and only one-fourth of all patients had an SPC contact before death. Interestingly, however, contact with SPC was associated with a lower proportion of patients requiring emergency care or hospitalization in secondary care during the last month of life.

These nationwide results imply that the need for palliative care remains unrecognized. Our results are in line with previous studies showing that patients with MM receive less palliative care and that it is initiated at later stages of the disease [5, 11–13]. Furthermore, patients with MM tend to receive more aggressive care at the end of life than patients with solid tumors [5, 11–13]. Potential contributing factors include the unpredictability of the illness trajectory, specific treatment needs such as blood transfusions, and occasionally, hematologists' unrealistic expectations regarding MM treatment [9]. Earlier contact with SPC has been shown to improve the quality of care, reduce pain intensity over time, and decrease the aggressiveness of end-of-life care, with comparable survival among patients with MM regardless of whether they received SPC [4, 9].

Our nationwide study demonstrated that most patients who received SPC lived in urban areas. The reason for this is probably multifactorial, but in 2019, palliative care services were mainly available in larger cities, and the specialized palliative home hospital services did not cover rural areas.

In our study, most patients with MM died in the hospital (81%). This aligns with national data for all cancer patients in Finland, where 82% died in the hospital [27]. This proportion exceeds rates observed in several Western European countries—26% in the Netherlands and New Zealand, 44% in England, and 73% in France—while remaining lower than the 87% observed in South Korea [30]. Previous studies among MM patients have similarly shown high hospital death rates. A nationwide United States study by Abbasi et al. [31] using the National Inpatient Sample found that 47% of patients with MM died in the hospital, a higher proportion than in the general population. In Canada, a population-based cohort of 5095 patients with MM reported that half of the patients died in hospital during a 13-year study period, and 65% were hospitalized in the last 30 days of life [11]. Overall, our higher proportion of in-hospital deaths may reflect limited SPC availability across Finland.

Notably, in our study, SPC was associated with a lower proportion of hospital deaths, with more patients dying in SPC settings instead. Similarly, Howell et al. [32] reported that referral to SPC services was linked to an increased likelihood of dying in hospice or at home. Furthermore, in a large United States cohort of 12 686 older patients with MM, 48% received hospice care, and among them, the median hospice stay was only 13 days. However, patients enrolled in hospice had lower odds of receiving aggressive treatment at the end of life [10].

In our cohort, the utilization of healthcare services during the last 6 months before death was very high: over 90% of patients had contacts with emergency departments, and over 80% had secondary care hospitalizations. This high use of healthcare services and contacts with emergency care may be related to the substantial symptom burden faced by patients with MM at the end of life, the more aggressive cancer treatment strategies applied during this period, and their comparatively limited access to SPC compared with patients with solid tumors [9–12].

In our nationwide cohort, SPC contact was associated with fewer emergency department contacts and fewer secondary care hospital admissions in the last month of life compared with patients without SPC contact. This effect was evident among patients whose first contact with SPC occurred at least 1 month before death (median 122 days before death). In contrast, late referral during the last month of life did not allow sufficient time to reduce healthcare utilization, although it may still have improved the quality of care. These findings are consistent with previous studies involving patients with cancer [19, 21, 24, 27, 33, 34] and align with a single-center study from Stockholm, Sweden, by von Bahr et al. [35], which specifically examined patients with hematological malignancies and found that SPC contact was associated with a decreased likelihood of emergency department visits and dying in an acute hospital. In our study, no difference was observed in primary care hospitalizations between the groups, likely because home deaths were rare and primary care typically provides general palliative care and end-of-life care. Importantly, in our study, SPC reduced hospital deaths (84% vs. 69%) and enabled 25% of patients with SPC contact to die in an SPC ward.

The major strength of this study is its nationwide, population-based design, covering all the patients who died of MM in Finland in 2019. Data were obtained from a national standardized Causes of Death Register and comprehensive healthcare registries, which are mandatory across all levels of health care. Linking these registries enabled access to detailed information on healthcare utilization and SPC contacts throughout all levels of care. We acknowledge several limitations. This was a retrospective register-based study, which limits the ability to infer causality between SPC timing and healthcare outcomes. In addition, we lacked access to detailed patient characteristics such as socioeconomic background, comorbidities, and other clinical information. While our findings are applicable to the Finnish healthcare system, their generalizability to other healthcare systems might be limited.

5 | Conclusion

This nationwide register-based study revealed that contact with SPC was associated with reduced acute healthcare utilization, particularly fewer emergency department visits and secondary care hospitalizations, as well as reduced hospital deaths, directing end-of-life care toward SPC units among patients with MM. However, many patients with MM still die without SPC contact, or the contact occurs late for them, which emphasizes the importance of recognizing the need for palliative care in this patient population. Early collaboration between hematologists and palliative care specialists is crucial for improving patients' end-of-life care.

Author Contributions

M.N., H.-R.L., T.S., and T.C. performed the material preparation and data collection. H.-R.L. conducted the statistical analysis. A.H. wrote the original draft of the manuscript. All authors contributed to the interpretation of results, as well as drafting and revising the manuscript. All authors approved the final version of the manuscript and agreed to be accountable for all aspects of the work, ensuring the accuracy and integrity of the presented data.

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Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data supporting the findings of this study are obtained from the Finnish Institute for Health and Welfare, but restrictions limit the availability of this data, as they were accessed under a license for the present study and therefore cannot be made publicly available. Data access can be requested from the Finnish Social and Health Data Permit Authority, Findata (info@findata.fi).

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