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The specialist palliative care team as a local resource

by Anita Chakraborty, Kalli Stilos

ABSTRACT

Background: Specialist-level palliative care support is intended for patients with complex physical and psychosocial needs. In addition to direct clinical care, specialist teams can be utilized to support the delivery of community-based palliative care by providing 24/7 access to advice and support for primary care providers, patients, and their families.

Aim: This paper describes how a specialist palliative care team, based in a tertiary level hospital, can provide timely access to palliative care for patients in a surrounding sub-region that has historically lacked a robust network of community-based palliative care supports.

Design: A retrospective database analysis was conducted from January 1 – December 31, 2019, to describe the demographic and clinical characteristics of patients referred to the Palliative Care Consult Team who reside in the sub-region of Scarborough, Ontario. Data were reviewed to highlight the role the team plays in supporting end-of-life care for this community of patients, families, and providers. Patients referred to the Palliative Care Consult Team with a residential address within the sub-region of interest were the focus.

Results: In total, 343 patients living in the selected sub-region were seen by the Palliative Care Consult Team during a 12-month period, representing 18% of the team's annual clinical volume. The majority of these patients (94%) had a cancer diagnosis. Median Palliative Performance Scale score at time of initial consult was 40 for inpatients and 60 for ambulatory patients. More than half the patients (56%) were "full code" at the time of initial palliative care consultation. Median survival from initial consult to death was 18 days for inpatients and 68 days for ambulatory patients. More than half of the patients (54%) died in a palliative care unit, with a smaller percentage dying in the home setting (7%).

Conclusions: Our report highlights the utilization of a database as a quality improvement tool to illustrate our institution's palliative care mission and vision of engaging in the provision of palliative care expertise to community-based patients and healthcare colleagues.

Keywords: palliative care, community, database, leadership, referral and consultation

KEY MESSAGE

A specialist-level palliative care team can support patients who reside in a region that lacks a robust community-based palliative care physician network. Validated quality indicators help guide the provision of high-quality palliative care at a systems level.

INTRODUCTION

With rapid advances in medicine and increasing life expectancies, people are living longer with a variety of chronic life-limiting illnesses. This trend has resulted in a growing societal demand for palliative care services tailored to meet the complex needs of a diverse patient population. However, many Canadians receive end-of-life (EOL) care in acute care settings (Gomes et al., 2013) due to various gaps that exist in the healthcare system. These gaps have

led to costly and low-quality EOL practices (Tanuseputro et al., 2015). The C.D. Howe Institute Report (2021) recommends steps that can be taken to address the inefficiencies identified and reduce acute care deaths at EOL by "creating appropriate and abundant discharge options for patients in acute care who are nearing the end of life" (p. 13).

One major driver of the utilization of acute care at EOL is the lack of available discharge options for patients who have chosen to adopt a palliative approach to care. These options could include palliative care home visiting programs, long-term palliative care beds, hospice facilities, and palliative care units within the geographical area where they reside. The lack of home-based supports is one of the major drivers of EOL acute-care utilization for patients who have chosen to adopt a palliative approach.

The delivery of high-quality palliative care is a priority for the Canadian healthcare system. Within the system, specialist palliative care providers represent a vital clinical resource, but one that is relatively limited. As such, various palliative care models have been proposed (Canadian Hospice Palliative Care Association, 2021). These models promote the development of palliative care competencies for primary care providers and generalist clinicians, as well as the implementation of interprofessional care models, which utilize the clinical expertise of advanced practice nurses. In our immediate geographical area, community healthcare, including palliative care, is organized and delivered via Local Health Integration Networks (LHINs), which are composed of smaller sub-regions. However, home palliative care physician resources vary between sub-regions, such that some have a robust network of home visiting physicians while others have inadequate physician coverage.

In this paper, we describe how our specialist Palliative Care Consult Team (PCCT) responds to the gap in access to specialist-level palliative care physicians in the home setting experienced

AUTHOR NOTES



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by patients in the sub-region. Our mission is to provide care that is consistent with our provincial and institutional palliative care standards, including that of timely access to palliative care support. The PCCT has implemented a model of care that supports a patient population residing outside the immediate hospital catchment area, in a nearby healthcare sub-region. The PCCT provides direct clinical care and 24/7 telephone support to patients, families, and primary care providers in this sub-region.

Clinical vignette

The following clinical vignette describes a common experience of a patient living in the sub-region who requires home palliative care expertise and illustrates how the PCCT addresses those needs.

Mrs. J.A. is a 53-year-old woman with a diagnosis of metastatic non-small cell lung cancer, whose disease has progressed despite several lines of chemotherapy and targeted therapy. She is admitted to hospital with worsening shortness of breath (SOB) secondary to a large right pleural effusion. She undergoes a therapeutic thoracentesis and placement of a pleural catheter. During her admission, Mrs. J.A. is referred to the PCCT. The PCCT physician and/or the advanced practice nurse see her daily during the hospitalization to manage her SOB. She is prescribed oral hydromorphone to provide symptomatic relief of breathlessness.

While exploring her goals of care, Mrs. J.A. explains that her wish is to return home and focus on symptom management and comfort for whatever time she has remaining. She reveals that she suffers from significant anxiety, which interferes with sleep and exacerbates the shortness of breath. Her goal is a home death; she wants to avoid returning to hospital, but worries she doesn't have enough support to stay at home. At the time of discharge, Mrs. J.A. is referred to the home-based palliative care nurse practitioner (NP). Given human resource limitations in the community-based home care service, there will be a two-week gap between discharge and home visitation by the NP. Mrs. J.A. is aware that the PCCT physician is available to provide 24/7 telephone support to her in the interim.

Three days after discharge, the PCCT physician receives a call from the home

care coordinator indicating that Mrs. J.A. has deteriorated rapidly and is experiencing increased effort to breathe even with the current symptom management regimen and drainage of plural fluid. Her anxiety is exacerbated by the high symptom burden. The PCCT physician arranges for a hydromorphone infusion and benzodiazepines to be initiated urgently in the home. The physician calls the patient daily and provides medical orders to the home RN and advocates for an urgent NP visit. Mrs. J.A. stabilizes over the next few days. A week later, the family calls saying the patient died at home and was pronounced by the home visiting RN. The PCCT MD courier a death certificate to the funeral home. Bereavement care to Ms. J.A.'s family is offered.

BACKGROUND

In response to the growing demand for palliative care expertise, the delivery of coordinated palliative care services remains a priority for Canada's healthcare system (Canadian Hospice Palliative Care Association, 2021). Nationally, it has been recognized that an imbalance exists between high clinical demand for palliative care and limited specialist resources. In response, various levels of palliative care supports have been outlined, which include primary, secondary and tertiary level care. Primary and secondary level care is typically provided by generalists, primary care physicians and advanced practice nurses including NPs. Tertiary care includes specialist level palliative care support, which is intended for patients with complex physical and psychosocial needs. In addition to direct clinical care, specialist teams can be utilized to support the delivery of community-based palliative care by providing 24/7 access to advice and support to primary care providers, patients, and their families.

Several palliative care quality indicators have been developed and validated to help guide the provision of high-quality palliative care at a systems level (Canadian Hospice Palliative Care Association, 2021; Henson et al., 2020). These indicators can be used to illustrate where palliative care is functioning well and where gaps continue to exist

in a region. Health Quality Ontario's (2020) quality standard highlights "timely access to palliative care supports" as one such indicator. Palliative care cohorts experience complex and often unpredictable needs and, as such, require routine access to 'around-the-clock' care. On-call coverage including evening, overnight, and weekend coverage may include telephone calls from a health provider, a number for patients and their families to call when pain or symptoms are not well managed, or to request a home visit.

The PCCT at Sunnybrook Health Sciences Centre functions within a tertiary level academic hospital, which includes a regional cancer centre and trauma program. The PCCT provides specialist level palliative care to both malignant and non-malignant populations in the acute care and ambulatory settings, including those patients who are transitioning to home palliative care. The PCCT operates using an interprofessional care model, as recommended by the Canadian Society of Palliative Care Physicians' staffing guidelines (Henderson et al., 2019). The core clinical team consists of physicians, an advanced practice nurse, registered nurses in the ambulatory setting, and a part-time social worker. Spiritual care support is provided by unit-specific chaplains. As a service, the team supports patients who wish to avoid acute care visits, including emergency room visits, admissions to hospital, and death in hospital. This is a common focus of other palliative care teams across the healthcare system (C.D. Howe Institute, 2021).

Our team has been proactive in aligning its vision and mission with palliative care priorities identified at the provincial and corporate level. Operational and clinical leadership teams at our organization are committed to providing high-quality palliative and EOL care (Stilos et al., 2016; Lau et al., 2018). Palliative care has been identified as a priority in our hospital's quality improvement plan, including the goal of "ensuring timely care matched to palliative care needs", which is aligned with Health Quality Ontario's (2020) quality standard. In addition, our institution's corporate quality

improvement plan includes “Quality and Related Health System Integration” as a priority area (Sunnybrook Department of Family and Community Medicine, 2021). The vision for this strategic pillar is to improve patient outcomes and experience by fostering a culture of collaboration and integration amongst our acute care institution and community partners, agencies, patients, and their families.

The PCCT aims to support the corporate vision by assuming a leadership and resource role for our surrounding communities and sub-regions. The leadership role includes many aspects such as providing direct clinical care for patients with the most complex needs, program administration, teaching and education, research, quality improvement, and specialist level mentoring and support for primary palliative care providers in the community. Wynnychuk et al. (2012) demonstrated that 68% of patients referred to the PCCT between 2007–2011 were living outside the hospital’s catchment area, which was more than double the number of referrals to the PCCT for patients living within the hospital catchment area. In particular, one sub-region (Scarborough) has historically been underserved in terms of community-based palliative care supports, including lack of a consistent roster of palliative care physicians available to provide EOL care for patients dying at home.

Given the PCCT’s leadership role in supporting patients and families in achieving a home death and our model of working with community partners to deliver high-quality palliative and EOL care consistent with HPCO quality standards, we support patients and families who reside in this sub-region that has historically lacked home palliative care physicians who are required to achieve a home death. The PCCT addresses this gap by providing access to 24/7 specialist palliative care support, pain and symptom management, and EOL care.

PURPOSE

This article 1) describes the demographics and disease characteristics of the patient population referred from the sub-region, 2) highlights the role the PCCT plays in supporting EOL care for this community of patients, families,

and providers who are relatively underserved by home palliative care physicians, and 3) discusses how a patient database contributes to monitoring the care delivered by the PCCT program.

METHODS

The Sunnybrook PCCT maintains an electronic patient database using Microsoft Access, which is housed on a secure internal server, is password protected and only accessible by PCCT administrators (Stilos et al., 2016). All patient data are collected on a comprehensive standardized data collection form and entered into the database by the administrative team. Baseline data elements for each patient include demographic information, primary palliative care diagnosis, referring service, and palliative performance scale (PPS) score. The PPS is a validated tool used to assess a patient’s functional performance and determine progression toward end of life (Baik et al., 2018.). Clinician estimate of survival (CES), and date and location of death are added, if known.

To help us delineate the needs of the sub-region’s population, an initial retrospective database analysis was conducted by the administrative assistant (FL). This audit provided a high-level description of the demographic and clinical characteristics of patients referred to the PCCT. Simple descriptive statistics were carried out to review the demographics and characteristics of patients referred from the sub-region. All patients referred to the PCCT from January 1–December 31, 2019, whose postal code was within the Scarborough sub-region, were included in this retrospective review.

RESULTS

During 2019, 343 patients living in the Scarborough sub-region were referred to the PCCT (Table 1), including patients admitted to acute care and those seen in the ambulatory setting. This represents 18% of the PCCT’s total new patient volume for 2019 (N = 1885). The year 2019 saw the lowest number of patients referred from this sub-region over a five-year period (Appendix 1). More than half of the sub-region

Table 1

Patient Characteristics

Patient Demographics (Both IP and OP)	#	%
Age		
<65	116	34
65-84	184	54
85+	43	13
Total	343	
Gender		
Female	200	58
Male	143	42
Total	343	
Disease		
Malignant	323	94
Non-Malignant	20	6
Total	343	

patients (58%) were female and two-thirds (67%) were older than the age of 65. Of the 343 new patients, 54% were initially seen as inpatient consultations, whereas 46% were seen initially in the ambulatory clinic.

The majority of patients (94%) referred from the sub-region had a cancer diagnosis. The most common malignant disease sites for acute care and ambulatory settings respectively were gastrointestinal (23% and 21%), genealogical (18% and 16%), and lung cancers (17% and 20%; Figure 1). For non-malignant diseases (Figure 2), cardiovascular disease was the most common (4%) diagnosis within the inpatient referrals, followed by neurodegenerative disease (11%), chronic renal failure (11%), and trauma (11%). As expected, only a small number of ambulatory patients (10%) were referred with a non-malignant diagnosis. During the time period covered by the audit, the PCCT had only recently established non-malignant palliative care clinics, including congestive heart failure (CHF), nephrology, and amyotrophic lateral sclerosis (ALS).

Figure 1

Malignant Disease Sites Referral Volumes

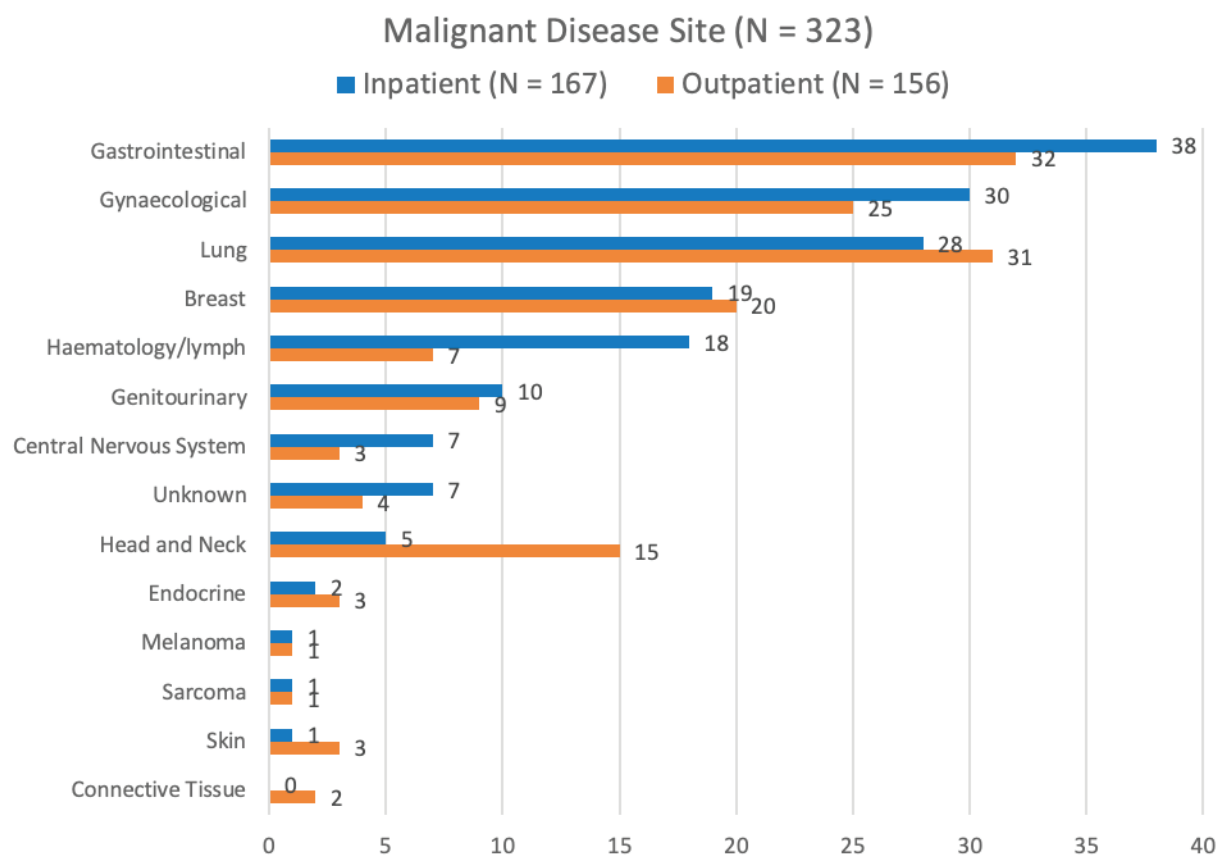
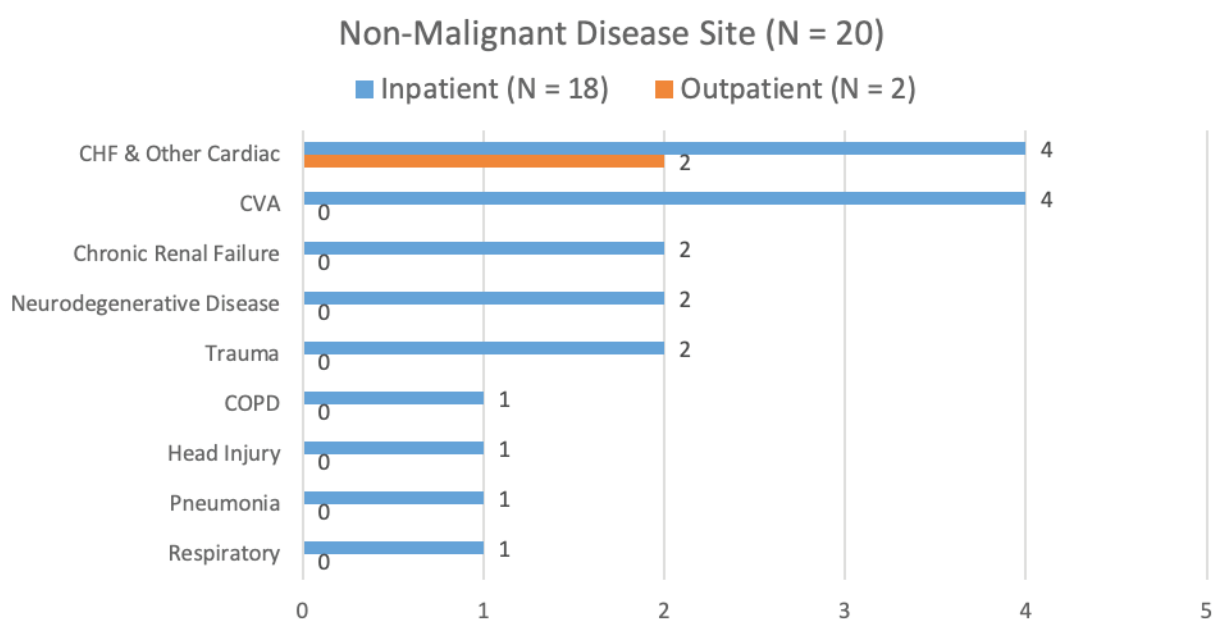


Figure 2

Non-Malignant Disease Site Referral Volumes



The median PPS score at the time of initial consult was 40 for inpatients and 60 for ambulatory patients (Figure 3), corresponding to patients in the “transitional” and “stable” zones on this scale. The PPS tool allows clinicians to estimate patient survival by looking at the

five functional dimensions: ambulation, activity level and evidence of disease, self-care, oral intake, and level of consciousness (Baik et al., 2018). The PCCT provides a clinician estimate of survival (CES) at the time of initial referral and consult (Figure 4), grouped into

the following categories: > 12 months, 3–12 months, < 3 months, 1–4 weeks, days (< 1 week) and hours (Table 2). For patients referred from the sub-region, median CES were < 3 months for inpatients and 3–12 months for ambulatory patients.

Figure 3
Palliative Performance Scale (PPS) at Initial Consult

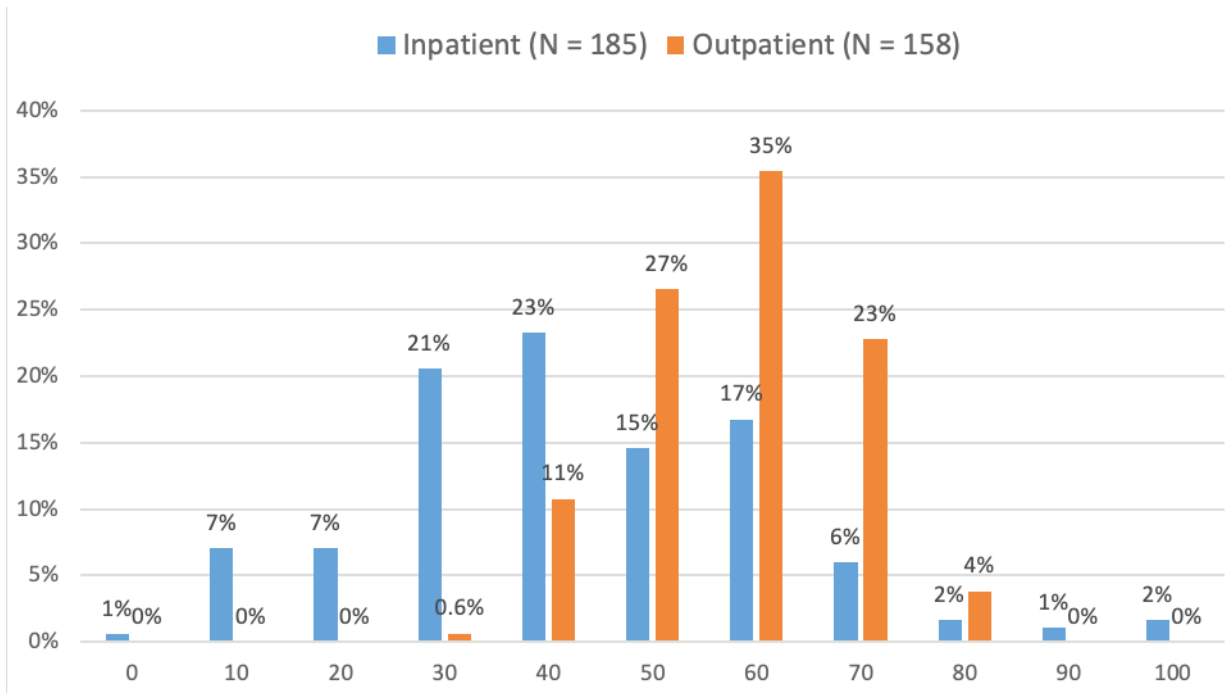


Figure 4
Clinician Estimate of Survival (CES) at Initial Consult

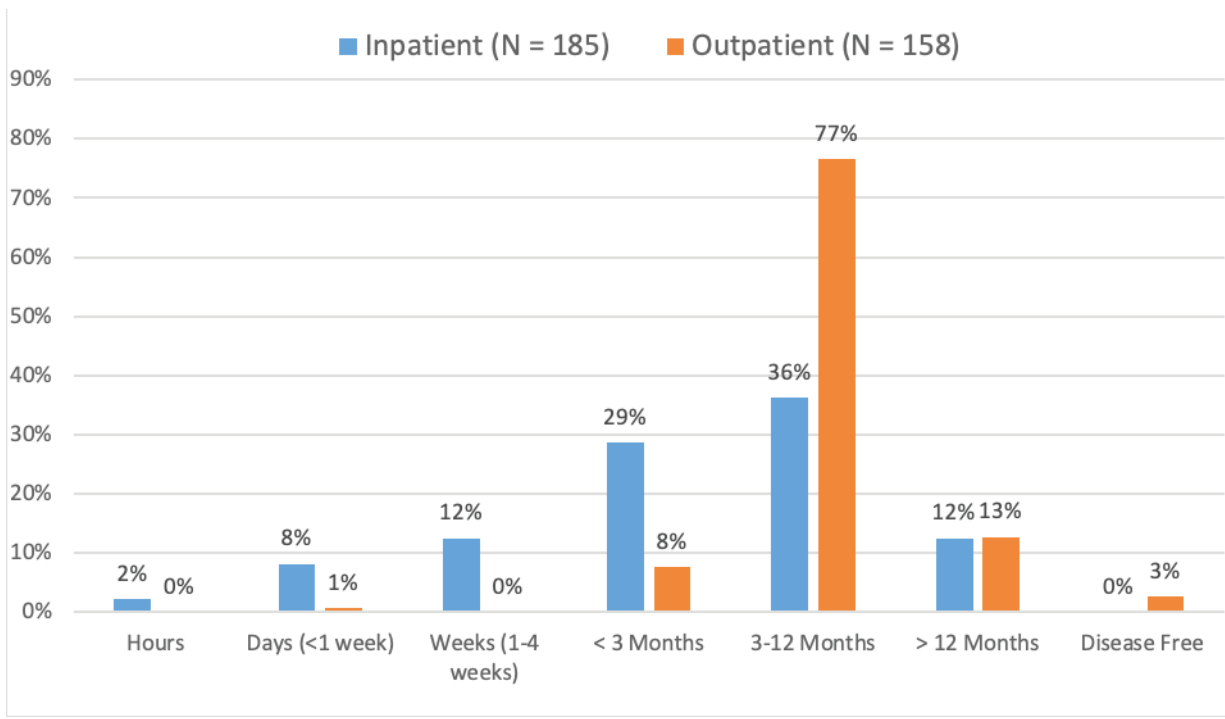


Table 2

Time From Palliative Care Consult to Death

Time Frame	Inpatient	%	Outpatient	%	Total
Hours	4	3	0	0	4
Days (< 1 week)	29	24	3	8	32
Weeks (1–4 weeks)	42	35	7	19	49
< 3 Months	26	22	11	30	37
3–12 Months	16	13	16	43	32
> 12 Months	2	2	0	0	2
Total	119	100	37	100	156

Code status at initial consultation was captured for inpatients only. Greater than half of the referred inpatients (56%) were “full code” at the time of initial palliative care consultation. Median survival during the interval from initial PCCT consult to death was 18 days for inpatients and 68 days for ambulatory patients. Of those patients who were initially seen in the ambulatory setting and subsequently died, more than half (54%) died in a palliative care unit, 27 % died in an acute care setting, and 16% died at home (Figure 5). For those patients initially seen in the acute care inpatient setting who subsequently died, just over half (54%) the patients died in a palliative care unit, one-third (35%) died in acute care, and only 7% died at home (Figure 6).

DISCUSSION

How we support the community

Specialist palliative care providers should be integrated into a model of care that is responsive to the complex physical and psychosocial needs of patient and families (Henderson et al., 2019). In addition to providing direct clinical care to patients with the most complex needs, specialist teams need to support and mentor primary teams in the community, including NP’s. When primary health teams have access to and support from palliative care specialists, they should be able to manage most patients requiring basic palliative care (Canadian Hospice Palliative Care Association, 2021).

Figure 5

Location of Death (Ambulatory Patient Cohort)

■ PCU (N = 20) ■ In hospital (N = 10) ■ Home (N = 6) ■ Other (N = 1)

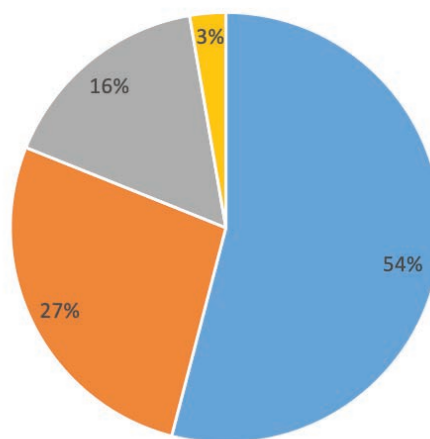
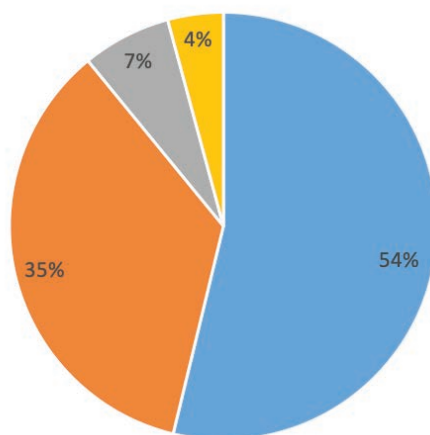


Figure 6

Location of Death for Inpatient Cohort

■ PCU (N = 64) ■ In hospital (N = 42) ■ Home (N = 8) ■ Other (N = 5)



One of the main barriers faced by many sub-regions is the lack of consistency, communication, and coordination of care between various healthcare providers (Seow et al., 2010). Often, there is no designated “most responsible provider” available to ensure comprehensive clinical oversight (Ronson, 2011). In our situation, the PCCT takes on the role of “the most responsible physician” by acting as a specialist resource to the NP who is the primary home palliative care provider. Support is provided through 24/7 telephone advice and guidance relating to pain and symptom management and comfort care at end of life, as well as assistance with complex decision-making that is often inherent in palliative care.

Place of death

Location of death has been a priority focus in our organization’s ongoing commitment to high-quality palliative care. Significant effort has gone into operational measures intended to expedite patient transfers from acute care to the Palliative Care Unit. Although place of death is an important QI indicator (Canadian Hospice Palliative Care Association, 2021; Henson et al., 2020) a “good” death includes many additional factors, including the provision of expert clinical care and adequate resources provided in any care setting. Health policies must recognize that decision-making at EOL is inherently complex and especially challenging when palliative care is not integrated, coordinated or consistent across sectors (Dudgeon et al., 2007). Multiple barriers, including socioeconomic resources, environment of care, and family dynamics, may impact a patient’s choice about location of death (Pollock, 2015).

Our experiences indicate that a “good” home death requires significant financial, medical, and logistic resources that are beyond the reach of many patients and families, thereby making a home death less feasible and desirable in some instances. However, when palliative care can be delivered in a community setting (in the patient’s home), the chance of dying in hospital decreased by half (Tanuseputro et al., 2018). The majority of patients from the

Scarborough sub-region died either in a PCU or home setting (63%). A previous retrospective study (Stilos et al., 2016), reviewing the characteristics of patients referred to the PCCT for end-of-life care over a four-year period (2008–2012), found that 50% of patient’s died in acute care within 72 hours of referral. This trend is moving in the right direction, as avoidance of death in an acute care setting should be a goal whenever possible.

Database impact and value

Finally, our review highlights the importance of an operational database in supporting program growth and development. Previous authors have reported on the utility of a team database in program development (Radwany et al., 2009; Weissman et al., 2008), and the C.D. Howe Institute Report (2021) supports the “identification and tracking of relevant metrics for appropriate EOL care” (p. 13). Data collection and analysis benefit program standardization, strategic planning, and quality improvement. The Centre to Advance Palliative Care encourages palliative care programs to explore key program components, such as operational, clinical, customer, and financial metrics, to ensure program quality and sustainability (Weissman et al., 2008).

PCCT utilizes the database as a quality improvement tool to meet the evolving demands of patients, referring services, and the corporate palliative care mission and vision. Patient volumes and referral patterns are reviewed annually to guide program expansion and human resources planning. Establishing a successful palliative care consult service has been achieved through an ongoing process of updating, maintenance, and analysis of the database. However, we recognize that the database in its current form falls short and does not reflect the total impact the PCCT has on the quality of care delivered.

The PCCT database allows for the prospective collection of high-level demographic and clinical characteristics of the patients we serve. Based on the data, the service can monitor trends in patient volumes and ensure adequate

PCCT human resources to meet clinical demand. However, this work also highlights the limits of our current database, namely a lack of detailed understanding of the palliative care needs and perceptions of the patient and families we serve, and the workload generated by those needs. Based on our preliminary findings, we suggest a comprehensive needs assessment be performed, including internal and external stakeholders such as PCCT clinicians, community care providers, patients, and families.

In addition, qualitative data regarding patient needs are not captured in the database. Based on our preliminary findings, we recommend a formal needs assessment be conducted to define and prioritize the needs of both patients and community care providers. Semi-structured interviews and focus groups with internal and external stakeholders would provide rich qualitative data to guide future program development and service delivery. Our current work reveals that we need a more thorough understanding of patient and provider experiences, including strengths and gaps in care. In this way, formative data could help PCCT and community providers to work collaboratively to better meet the needs of this population.

Additionally, clinician workload and specific activities are not captured. Specifically, the database does not document the amount of time each PCCT member spends on the phone with a patient/family member and/or nurse coordinator, and indirect time (faxing and calling in prescriptions, etc.), both of which are to meet the demands of this patient population. Moving forward, the PCCT has committed to a quality improvement project that will log the details of all encounters with Scarborough patients to gain a true appreciation of the time and effort invested in providing care.

CONCLUSION

The PCCT provides specialist level palliative support to patients who reside in a sub-region that is located beyond our institution’s geographical catchment area. We support this cohort of patients, families, and community providers by offering 24/7 expert pain and

symptom management, EOL care, and support during critical transitions in care. Our data indicate that 63% of patients from this sub-region who are followed by PCCT are able to die in a PCU or home setting. The PCCT

provides 24/7 support to NPs who function as the primary palliative care providers in the home. Using this model of care, the PCCT is aligned with the hospital's quality improvement goal of supporting our community partners and

also the corporate vision of palliative care leadership within our community. The review highlights the importance of a clinical database to support the growth and development of a palliative care consult service.

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Appendix 1

Year	Number of Scarborough Patients	Total Unique Palliative Care Patients	Percentage of Scarborough Patients
2015	335	1697	20%
2016	356	1667	21%
2017	390	1699	23%
2018	415	1778	23%
2019	343	1885	18%