

Research Article





Palliative care utilization in patients with newly diagnosed, incurable solid tumor malignancies: experience of an institution new to palliative care

Abstract

Background: Early palliative care referral can enhance quality of life in patients with metastatic cancer and even improve overall survival in non-small cell lung cancer. Despite compelling data showing benefits of early integration of palliative care, institutional barriers to care exist. Our institution recently established an outpatient palliative care service. To improve utilization of this new service, we identified clinicians' attitudes and barriers to palliative care and provided education on the referral process. The effects of this intervention on palliative care utilization were assessed.

Methods: A retrospective chart review was completed on outpatient medical oncology referrals to identify patients referred for newly diagnosed, solid tumor malignancies with no curative options. Hospice referrals were excluded. Clinicians participating in multi-disciplinary tumor boards were surveyed to identify referral practices and attitudes/barriers to palliative care referrals. Education on this service and the referral process was provided during the survey period. Post-intervention review of referrals over four months was conducted.

Results: There were 53 new, pre-intervention consultations meeting study criteria, and only three (5.7%) patients were referred. Our survey revealed that 66%(31/47) of oncology providers did not know the institution had onsite palliative care available and only eight (17%) knew how to place a referral. After education was provided, a second cohort revealed 24.1%(7/29) of patients were referred for outpatient palliative care representing an 18.4% absolute increase.

Conclusion: We significantly increased palliative care referrals for medical oncology patients with advanced or metastatic disease. However, other efforts to improve institutional awareness and change the culture of care are needed to ensure that majority of these patients are appropriately referred. Longitudinal evaluation will further ensure that timely adjustments are made and that effects are permanent

Keywords: palliative care, solid tumor cancers, military medicine

Abbreviations: PC, palliative care; QoL, quality of life; NCCN, national cancer care network; ASCO, american society of clinical oncology; ESMO, European society of medical oncology; EMR, electronic medical record

Introduction

Palliative care (PC) is the medical specialty that focuses on improving quality of life through managing pain and other distressing symptoms of a serious illness.¹ Patients with advanced cancer are often candidates for PC and may benefit significantly from access to the multi-disciplinary approach employed by this specialty. In particular, PC has been shown to improve outcomes related to pain, depression, anxiety and other symptoms. Other identified benefits include caregiver satisfaction and decreased hospital admissions among patients with advanced cancer.^{2,3} In the setting of metastatic non-small cell lung cancer, early PC referral is associated with improved overall survival.⁴

Early initiation of PC is important in the management of advanced illness because it allows for a proactive approach in identifying and

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addressing distressing symptoms early in their development. Several studies have shown improved quality of life (QoL) outcomes for both patients and their caretakers, when this intervention is integrated early in the course of the disease process.4-6 Increasingly, these benefits have been recognized by various professional bodies in the form of consensus statements and guidelines endorsing referral to PC.7,8 However the definition of early PC referral is not well established. Temel et al.4 defined early PC in their landmark study as referral to PC that is nearly simultaneous with initial oncologic evaluation. Patients were seen by a PC provider within three weeks of enrollment.⁴ Another study defined "early" referral as within three months of diagnosis of advanced cancer or three months prior to death.9 The most recent National Cancer Care Network (NCCN) Palliative Care Guidelines identify a diagnosis of metastatic solid tumor malignancy as an indication for PC referral. These guidelines also suggest that patients should be screened for PC needs both at the initial visit and at regular intervals thereafter.¹⁰ Similarly, the American Society of Clinical Oncology (ASCO) Clinical Practice Palliative Care Guidelines now recommend PC involvement within eight weeks of diagnosis of an advanced malignancy.5

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The role of PC in oncology, along with the attitudes of oncologists toward PC, has evolved over recent years. A 1998 survey by ASCO found that 20-25% of oncologists reported end-of-life care as the worse part of the oncologists' experience, highlighting the challenge of managing this component of cancer care. Despite the challenges and frustrations inherent in providing necessary end-of-life care to terminal cancer patients, most oncologists felt that it is an important aspect of their practice.¹¹ This perception was demonstrated in a 2003 European Society of Medical Oncology (ESMO) survey of medical oncologists. This study revealed that 75% of respondents felt that a medical oncologist is the "best person" to coordinate PC of patients with advanced cancer, and the majority of responders felt they were competent in managing symptoms of advanced cancer.¹² Only 32% of the responding medical oncologists in this survey reported collaborating "often" with PC specialists. However, there was general consensus that PC should be initiated early or incorporated during the active treatment phase of advanced cancer. Despite the recognition of the importance of integrated PC, barriers toward the utilization of this service have persisted in the decade following that study, with a recent survey identifying similar attitudes among oncologists.13 ASCO and ESMO both established policy statements that provide a framework of the oncologist's responsibility in providing PC, emphasizing the collaborative nature of this care and the importance of developing the skills necessary to assess and manage distressing symptoms.14,15

Barriers to early PC access are numerous encompassing patient, physician, and medical system related factors.¹⁶ A survey of oncology providers at MD Anderson Cancer Center revealed that the term 'palliative care" itself is associated with many negative connotations, including a sense of surrendering, and may be perceived to be more distressing and hope-reducing when compared to the term "supportive care".¹⁷ Some respondents in this survey reported an increased likelihood to refer a patient to a service named "supportive care" rather than "palliative care". Military service is associated with a unique set of life stressors, burdens, and service related injuries, along with shared experiences and value systems, which emphasize the importance of access to care for our service members.¹⁸ The diagnosis of a terminal cancer in a military member or their loved one can pose additional challenges which may impact their QoL and performance in the military. Until recently, PC has not been a part of the continuum of services available to military members. The aim of this study was to assess attitudes and barriers to PC utilization among physicians in a newly established outpatient PC service within a military health system, and evaluate whether providing physicians with PC education improves PC utilization.

Materials and methods

This study is a quality improvement project utilizing a retrospective chart review among patients enrolled in a large medical network serving the needs of 240,000 beneficiaries. An electronic medical record (EMR) review was conducted on outpatient medical oncology referrals with the following inclusion criteria: newly diagnosed, advanced or metastatic solid tumor malignancies with no curative local treatment options. Medical records were reviewed to determine whether PC consultation was offered and utilized. A pre-intervention period included an initial EMR review for charts from January 1 to June 30, 2016. During this time, outpatient PC referrals had just become available to DoD beneficiaries at SAMMC. From 1 to 15 July, clinicians participating in multi-disciplinary tumor boards were surveyed to identify their PC referral practices as well as attitudes and barriers to referrals. Questions used in the pre-intervention palliative care utilization survey are shown in Table 1. Differences in practice patterns between surgeons and medical oncologists were also evaluated. Education and instruction on the services offered by PC were presented to oncology providers. The process on how to place a PC referral was also explained during this period. After this intervention, a second EMR review to re-assess physician PC referral practices took place from 17 July, 2016 to October 30, 2016.

 Table I Pre-intervention palliative care utilization survey questions

Questionnaire for referring providers

Are you aware that we can refer our patients to Palliative Care physicians?

□Yes □No

Do you know how to place a referral for Palliative Care?

□Yes □No

Have you referred any patients to Palliative Care in the past 6 months?

□Yes □No

How likely are you to place an outpatient referral to Palliative Care?

□Very Unlikely □Unlikely □Likely Very Likely

What are your perceived barriers to referring to Palliative Care?

Results

A total of 1,117 new consultations to medical oncology were reviewed. Eighty-two patients were referred to medical oncology for incurable solid tumor malignancies. In the pre-intervention period, 53 patients were seen and evaluated, and three patients (5.7%) were referred to PC. Physicians participating in various multi-disciplinary tumor boards were formally surveyed to identify referral practices, barriers and attitudes toward PC, along with knowledge of the referral process among various specialties involved in the care of cancer patients. In total, 47 physicians responded from the various specialties: colorectal surgery (2), cardiothoracic surgery (2), general surgery (4), gastroenterology (7), gynecology-oncology (1), orthopedics-oncology (1), otolaryngology (3), medical oncology (12), neurosurgery (4), pulmonology (5), radiation oncology (5), and surgical oncology (2).

Physicians taking the pre-intervention PC survey identified system barriers of "lack of understanding of the PC referral process" and "lack of awareness of PC referral availability" as the most common barriers to utilizing PC (Table 2). This survey revealed that the majority of physicians providing cancer care (66%) knew that the institution had onsite PC available. All responding medical oncologists were aware of outpatient PC availability compared to 58% of surgeons (Table 3). Only 17% of respondents knew how to place a referral. However, the majority of physicians (85%) reported that they were "likely" or "very likely" to refer to PC (Table 4).

Twenty-nine patients met inclusion criteria for the post-intervention EMR review. In this second cohort, 7 patients (24.1%) received early outpatient PC referrals. This represents an 18.4% increase (p=0.029) in referrals-all of which were from medical oncology physicians (Figure 1 & Figure 2). Of the 10 total patients referred to PC during the study time interval, 8 were referred within 8 days of their initial medical oncology appointment (Table 5). Two patients were referred more than 30 days after their initial appointment.

| Identified barrier | Example response | Number of responses | |
|---|--|------------------------|--|
| | "Misunderstanding of complementary concept of Palliative Medicine" | | |
| Role in setting of active treatment (e.g. perception that palliative care equates to hospice) | "Misunderstanding that care will stop" | 5 | |
| · ··· F.·· ··· · · · · · · · · · · · · · | "Knowing best hospice providers to refer to" | | |
| | "Don't know how" | | |
| Sustana hamian | "Confusion with current referral process" | | |
| Systems barriers | "Unclear how to refer at SAMMC" | 10 | |
| | "No inpatient PC at SAMMC" | | |
| | "Would expect to be handled by primary care" | | |
| Perception that this is the role of another provider | "If patient is an operable candidate, would not refer and if not an operable candidate would expect MedOnc to refer" | 3 | |
| | "Uncommon for surgical candidates to have end-of-life needs" | | |
| | "Very uncommon for ENT patients to have end-of-life needs" | | |
| | "Didn't know it existed at SAMMC" | | |
| Lack of awareness | "New staff so did not know all details" | 10 | |
| | "Didn't know about this option" | | |
| | "Forget about it during the encounter" | | |
| Other/patient factors | "No patients requiring PC services recently" | 8 | |
| | "Remembering that his is an option. Not an established pattern/practice" | | |

| 6 | Madhaal | | Staff (n=47) |
|--------------------|--------------------|---|--------------|
| Surgeons (n=19) | oncologists (n=12) | Aware that outpatient PC referrals exists | 66% |

 Table 4 Physician palliative care referral practice patterns

| | (n=19) | oncologists (n=12) | Aware that outpatient PC referrals exists | 66% |
|---|--------|--------------------|---|------|
| Aware that outpatient PC referrals exists | 57.90% | 100% | Aware of how to place a PC referral | 17% |
| Aware of how to place a PC referral | 15.80% | 25% | PC referrals in the past 6 months | 0 |
| PC referrals in the past 6 months | 0 | 16.70% | Likelihood of referring | |
| Likelihood of referring | | | 0= very unlikely | 0=2 |
| 0= very unlikely | 0=1 | 0=0 | I= unlikely | I=5 |
| l = unlikely | I=3 | I=0 | 2 = likely | 2=18 |
| 2 = likely | 2=9 | 2=3 | 2 11/01/ | 2 10 |
| 3= very likely | 3=6 | 3=9 | 3= very likely | 3=22 |

Table 5 Characteristics of referred patients

| Patient | Age | Gender | Diagnosis | Number of days from initial appointment to PC referral | Number of days from referral to PC appointment |
|---------|-----|--------|---|--|--|
| А | 42 | Male | Gastric Carcinoma | 0 | Patient later declined |
| В | 71 | Male | Non-small cell lung cancer (adenocarcinoma) | I | 12 |
| с | 57 | Female | Poorly differentiated carcinoma (presumed lung) | 0 | Died prior to appointment |
| D | 67 | Female | Breast Adenocarcinoma | 8 | 8 |
| E | 57 | Male | Non-small cell lung cancer (adenocarcinoma) | 0 | 4 |

Table Continued....

| Patient | Age | Gender | Diagnosis | Number of days from initial appointment to PC referral | Number of days from referral to PC appointment |
|---------|-----|--------|-------------------------|--|--|
| F | 78 | Female | Gastric cancer | 0 | 24 |
| G | 66 | Female | Renal Cell Carcinoma | 0 | Multiple phone messages left without returned call |
| н | 57 | Female | Cholangiocarcinoma | 0 | 38 |
| I | 55 | Female | NSCLC-Squamous | 64 | Patient later declined |
| J | 61 | Male | Prostate adenocarcinoma | 91 | 17 |



Figure I Pre-intervention PC referral practices.



Figure 2 Post-intervention PC referral practices.

Discussion

The most recent Committee on Cancer (CoC) standards recommends that onsite PC should vary depending on the "scope of the program, local staff expertise, and patient population."8 Here we describe the experience of a military health care facility in establishing an outpatient PC service. Lack of awareness of the existence of an onsite PC service appears to be the most prominent barrier to access identified in this study. Providing education on PC service availability and resources offered appears to have positively impacted the number of cancer patients who may potentially benefit from this type of care within our institution. PC referrals improved from 5.7% in the pre-intervention period and to 24.1% post-intervention. Despite this improvement, PC utilization at our institution remains relatively low in comparison to the 45% consultation rate reported at MD Anderson¹⁹ and a 52% referral rate reported in a retrospective review of patients with advanced pancreatic cancer.²⁰ In addition to the perceived barriers reported by our physicians in Table 2, other potential barriers may include misconceptions of the role of PC, an individual physician's lack of confidence in discussing PC issues with their patients, lack of inpatient PC services, and lack of visibility of this new service within our institution.

To our knowledge, the attitudes and perceptions of surgeons toward PC have not been previously described in medical literature. We evaluated pre-intervention survey responses to see if there was a difference in the attitudes and practice patterns between these groups of clinicians. Twenty-one percent (4/21) of surgeons responding to our survey reported that they would be "very unlikely" or "unlikely" to refer cancer patients to PC whereas all medical reported that they would be "likely" or "very likely" to refer. One general barrier identified in survey responses from some of the surgeons is the perception that cancer patients who are surgical candidates uncommonly have end-of-life needs. While patients with terminal cancer may undergo palliative surgical procedures, medical oncologists are uniquely positioned to identify an individual's PC needs due to their role in providing long-term follow-up and management. This may explain why all the patients in the post-intervention period were referred to PC by medical oncologists rather than the surgeons. Significant heterogeneity and general lack of consensus among medical and surgical oncology providers on the most appropriate candidates for referral to PC remain. Of note, the majority of patients (80%) referred for PC in this study were referred within a timeframe that would be categorized as early PC integration. Two patients were referred later in their care. Patient I initially had strong reservations toward the concept of palliative medicine, and Patient J was referred later in the course of his illness when he developed QoL changes related to therapy (Table 5).

Although we did not specifically assess patient-related factors our study, we do note that ethical and relationship issues can pose significant barriers to the initiation of PC. In particular, these factors can add to the difficulty of balancing the principles of patient autonomy, beneficence, and non-maleficence in the face of advanced cancer. The burden associated with chemotherapy, for example, can often be justified when there is "reasonable expectation of benefit" from said therapy "as long as it is offered in accordance with the individual's wishes".²¹ The transition from active treatment to supportive care can be particularly difficult within the context of the patient's relationship with their oncologist. There may be intense pressure to continue aggressive treatment to support a patient's hopefulness and resist formal involvement of PC, which may be interpreted as a form of abandonment. Physicians may fear this perception from their patients which may also constitute a barrier to referral. This may be of particular concern within the military community, where a strong esprit de corps exists and the "leave no man behind" attitude can pose as a unique barrier for PC referral. For these reasons, it may be helpful to assess our unique military population's attitudes to the concept of PC.

This study focused on referrals that were triggered by the diagnosis of terminal cancer to medical oncology, but there are clearly other potential candidates for referral that are not captured

by these criteria. A recent systematic review of the literature found that "cancer diagnosis, prognosis, physical symptoms, performance status, psychosocial distress, and end-of-life care planning needs" are important considerations in making this determination. However, there are no standardized assessment tools to guide referral criteria.²² The referral process has been identified as an essential domain of PC in the most recent ASCO guidance statement, suggesting that routine assessments of cancer patients should be conducted periodically to determine need for PC referral. Ideally, oncology centers should have "protocols to facilitate these assessments," and "maintain rosters of patients receiving palliative/comfort care and hospice care for purposes of improvement and outcome tracking.14" The recently published experience of one institution describes a potential strategy in which the presence of non-curative disease or poor performance status triggers the use of a 5-item screening tool that ultimately informs the clinician's decision to refer a patient to PC.23 This screening tool, the "distress thermometer," or an amalgamation of screening tools to fit our specific patient population and institutional capabilities may be helpful in determining which cancer patients may benefit most from an early PC referral.

Conclusion

Provision of education on PC availability and referral process improved utilization of this service at our institution. However, significant barriers remain which include physician misconception of PC and system barriers within an institution previously unfamiliar with PC practices. Periodic review of institutional policies and referral practices is important for maintaining an effective PC program. This process is especially important in the initial phase to ensure continued maturation of the service and improve comprehensive cancer care. Additional efforts are needed to improve institutional awareness and change the culture of care to ensure that the majority of our patients with terminal cancer diagnoses are appropriately referred to PC. Future efforts at our institution will focus on establishing and disseminating a practice policy with standardized screening tools to assist in clinician decision-making to identify appropriate patients for early PC referral for our cancer patients. Integrated PC within the SAMMC medical oncology clinic is being considered as a potential intervention to provide effective and timely PC. We also hope to expand the PC service to the inpatient setting and incorporate a PC rotation into the internal medicine residency curriculum. Continued longitudinal evaluation will further ensure that timely adjustments are made and that effects of these interventions are permanent.

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Conflict of interest

The author declares no conflicts of interest.

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