A Process Evaluation of an Outpatient Palliative Care Program: A Quality Improvement Project

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ABSTRACT

Palliative care has evolved from providing care for patients near end-of-life into a specialized discipline focused on addressing the physical, emotional, social, and spiritual needs of patients throughout the trajectory of an illness. For patients with metastatic cancer, timely referrals to palliative care are essential in order to have a meaningful impact on their quality of life. Recommendations for screening patients for palliative care have been offered by professional organizations; however, screening all patients with metastatic cancer poses many challenges. This quality improvement project conducted a process evaluation of an outpatient palliative care program and evaluated the feasibility of utilizing a screening tool in an effort to readily identify patients with metastatic cancer that have palliative care needs in an outpatient cancer center. Although nurses' compliance with the screening tool was less than expected, screening for palliative care needs in this setting resulted in more referrals to palliative care compared to physician referrals. Improvements in quality of life were found in patients who received a palliative care consultation and patients were very satisfied with the care provided by palliative care. The potential for financial improvements was observed as a result of this project.

Key words: *palliative care, metastatic cancer, screening, process evaluation*

INTRODUCTION

Palliative care has evolved from providing care for patients near end-of-life into a medical sub-specialty focused on addressing the physical, emotional, social, and spiritual needs of patients throughout the trajectory of an illness. Major professional organizations, including the Institute of Medicine (IOM) and the World Health Organization (WHO), have recognized the benefits of palliative care and have called for improved palliative care services across various healthcare settings. As a result, outpatient palliative care programs have been established with the goal of offering patients and their families improved quality of life by providing timely interventions to manage distressing symptoms, assisting with making medical decisions, and developing a plan of care that reflects patients goal, values, and preferences. Late referrals to palliative care have been, and continue to be, an issue faced by palliative care programs. Research has demonstrated that in order to have a meaningful effect on cancer patients' quality of life, palliative care must be provided early in the disease trajectory and concurrently with standard oncologic care.[1, 2] In a recent clinical guideline update, the American Society of Clinical Oncology recommends palliative care for both hospitalized patients and outpatients with advanced cancer.[3] Ideally, palliative care should be delivered along active treatment. This update is based on the most recent research investigating the efficacy of palliative care in patients with advanced cancer.[4, 5]

The focus of this quality improvement project is twofold; (a) to conduct a process evaluation of the program, (b) to investigate whether a new method of screening patients for palliative care needs in an outpatient infusion center results in a greater number of referrals to palliative care compared to the current referral process. The current referral process requires a physician referral. This project will examine the feasibility of using a screening tool to identify palliative care needs for newly diagnosed patients with stage III-IV cancer and for patients with recurrent cancer. Improving efficiency in the screening process will ensure cancer patients receive timely access to outpatient palliative care services.

BACKGROUND

Modern medicine has produced new and innovative therapies in the treatment of cancer. As a result, patients are living longer and some patients have been cured of their disease. However, this is not the case for a large number of patients, especially those with late stage cancers. For example, advanced lung cancer has a very poor prognosis with approximately 15% of patients alive 5 years after the initial diagnosis.[6] Survival rates for patient with advanced pancreatic cancer are even lower with a 5-year survival rate of 3% for stage III and 1% for stage IV.[7] Nevertheless, patients are often presented with new therapies or modalities that can slow the progression of cancer and lengthen lives even if survival is unaffected and quality of life is negatively impacted. As discussions of treatment options become the focus of patients' visits with their oncologists, conversations about quality of life and goals of care become overshadowed by the possibility of more treatment, even if treatment is not in the best interest of the patient. As patients proceed with treatment including chemotherapy and radiation therapy, side effects such as nausea, vomiting, pain, fatigue, depression, and anxiety are experienced. Poorly controlled symptoms can further exacerbate the psychological symptoms of anxiety and depression which can lead to unnecessary suffering and a decrease in quality of life.[8] Moreover, depression has also been found to increase cancer patients' mortality risk.[9]

Benefits of Palliative Care to Patients

Palliative care has evolved into a medical specialty which aims to improve the quality of life of patients with chronic and life-limiting illness. There is a growing body of evidence supporting the introduction of palliative care early in the course of a cancer diagnosis.[10, 11] In a landmark study, Temel et al[1] compared standard oncology care that incorporated early palliative care with standard oncology care alone and found significant improvements in patients' mood, quality of life and overall survival in the group that received palliative care. In addition to the improvements in symptoms, the authors also found that the patients who received palliative care documented their preferences for resuscitation which resulted in less aggressive care as patients entered their final phase of life. Yoong et al[2] found similar results in lung cancer patients when palliative care was integrated early with standard oncology care. Discussions of coping were a major component of the palliative care visits as well as building relationships and rapport with both patients and their families. This paved the way to discuss more of the difficult aspects of cancer care including illness understanding, prognostic awareness and resuscitation preferences.

Several studies investigating outpatient palliative care in cancer patients have emerged since the Temel et al[1] landmark study.[11, 12, 13] Zimmerman et al[5] conducted a cluster randomized trial of metastatic cancer patients and compared standard oncology care with early palliative care and standard oncology alone in an outpatient palliative care clinic within a cancer center. Results indicated statistically significant improvements in quality of life and satisfaction with care. An important aspect of the Zimmerman et al[5] study was the inclusion of patients with multiple types of cancer. Unlike the studies by Temel et al[1] and Yoong et al[2] which only included patients with advanced lung cancer, Zimmerman et al[5] included patients with lung, gastrointestinal, genitourinary, and breast cancers. Similarly, Dyar et al[11] included patients with metastatic breast and prostate cancer in their randomized pilot study. Temel et al[14] also included patients with newly incurable non-colorectal cancer and lung cancer in a randomized clinical trial study investigating the effects of early integrated palliative care. Results indicated greater improvement in quality of life and depression in both the lung cancer patients and the gastrointestinal cancer patients when palliative care was delivered early and concurrently with standard oncology care compared to the patients who only received standard oncology care. The introduction of early palliative care with standard oncology care clearly demonstrates palliative care's effectiveness in improving the quality of life of patients and their families as well as improving outcomes and overall satisfaction with care.

Benefits to the Health Care System

High-quality and cost-effective care are the goals of today's ongoing healthcare reform discussions. Oncology treatments are costly, thereby making it a central issue in the debate. Healthcare organizations are continuously looking to reduce costs without negatively impacting quality; this has become a priority as the nation moves from the traditional fee-for-service model to the population health management payment model. Research has indicated that palliative care reduces healthcare costs and is a viable model of care in today's healthcare arena.[15] Early involvement of palliative care helps avoid unnecessary hospitalizations, as well as reducing re-admissions.[16] The benefits of palliative care, for both patients and the national health care system, cannot be overemphasized and the growth of palliative care programs across different health care settings is evidence of the evolving discipline of palliative care.

Clinical Guidelines for Palliative Care

In 2012, the American Society of Clinical Oncology (ASCO) published their provisional clinical opinion which proposed a standard of care incorporating palliative care with oncologic care in patients with advanced cancer.[17] The decision to create a provisional clinical opinion was based on the strongest evidence at the time. Since the creation of ASCO's provisional clinical opinion, several randomized controlled studies have been conducted that indicate the benefits of early palliative care in patients with metastatic cancer.[18, 10, 19] As a result of these studies, ASCO developed clinical practice guidelines in 2016 for a combined approach of palliative care and oncologic care .[3] The guidelines call for timely referral to palliative care for both inpatients and outpatients with advanced cancer. [3] Newly diagnosed patients with advanced cancer should have palliative care involved within eight weeks of diagnosis.[3] Family members and friends needing a network of support can also be referred to palliative care. [3]

Screening Patients for Palliative Care

The National Comprehensive Cancer Center Network's (NCCN) palliative care guidelines recommend screening all patients for palliative care issues at the first visit with their oncologists and at subsequent, clinically relevant times. However, there are challenges in the process of screening patients for palliative care needs and screening all patients may not be efficient or effective.[20] Hui et al[21] conducted a systematic review of the literature and found a lack of consensus of which patients should be referred to outpatient palliative care. According to Glare et al[20] a better approach would be to base referrals on an assessment of need. In a pilot study utilizing a palliative care screening tool, the researchers found between 7% and 17% of patients attending an outpatient GI clinic resulted as having palliative care issues and 13% who might have benefited from having palliative care involved in their care.

METHODS

Setting

The setting for this process evaluation and pilot study took take place at the cancer center of a midsize healthcare system located in the northeastern region of the US. The ambulatory infusion center as well as the outpatient palliative care program is embedded in the cancer center.

Design

The design for this quality improvement project included a program evaluation to determine the current process of referring patients to the outpatient palliative care program. An aspect of the project included a pilot study to evaluate the implementation of a palliative care screening tool by nursing staff, to identify the palliative care needs of patients with recurrent cancer and newly diagnosed stage III-IV cancer in the ambulatory infusion center.

DATA COLLECTION AND ANALYSIS

Process Measures

Assessment of Inter-rater Reliability

Prior to full implementation of the screening protocol, a pilot study was conducted over a two-week period to examine the reliability of the screening tool performed by the infusion nurses. Education was provided in the form of didactic instruction. Once the staff was fully educated, screening of actual patients began. The nurse screened the patient followed by the palliative care specialist. Each infusion nurse was assigned an alphabet letter for identification purposes. Each infusion nurse was evaluated twice with two different patients to ensure reliable usage of the screening tool. The infusion nurses scores and the palliative care specialists scores were recorded with a data collection tool and loaded into the SPSS -24 statistical program. Scores were compared and analyzed to verify the inter-rater reliability. The Cohen’s Kappa statistic and percentage of agreement was used to analyze agreement between scores. For the purpose of this study, a Cohen’s Kappa between 0.61 and 0.8 was deemed as acceptable. Once the screening process was deemed safe and effective, implementation of the nurse led screening process began.

Implementation of Screening Tool

The infusion nurses utilized the Five-Item Palliative Care Screening Tool to identify patients with palliative care needs (Appendix A). The Five-Item Palliative Care Screening Tool is based on the palliative care guidelines from the National Comprehensive Cancer Center Network (NCCN). The Screening tool is freely available for private use and no permission was required for use in this project. The screening tool has undergone psychometric testing and has good internal reliability (Cronbach alpha .8) [20]. The screening tool is a five-item check list that assesses certain characteristics of cancer, patient's functional ability, and the presence of comorbid diseases. Scores range from 0-13. Glare et al[20] found that a score of five had the best predictive values. Any patient scoring five or above was referred to the outpatient palliative care program.

The screening took place during the infusion nurses' initial assessment, before any chemotherapy was administered. To complete screening, the infusion nurses used all clinical and relevant information that was available. Patients were not notified they were screened for palliative care but were notified if they were considered appropriate for referral to palliative care. The oncology providers were aware of the pilot study but did not utilize the screening tool. The oncologists continued the standard practice of referring to palliative care. Once the screening was completed and patients had met the minimum score of five, the infusion nurses called the outpatient palliative care office and made a referral. The palliative care office called the patient and scheduled an appointment.

A component of the process evaluation included examining the infusion nurses' compliance utilizing the screening tool. This was accomplished by comparing the total number of patients eligible for screening with the total number of patients successfully screened. The total number of referrals that resulted from the infusion center was also evaluated by monthly auditing. This total number was then compared against the total number of referrals that resulted from the standard referral process by the oncology providers.

OUTCOME MEASURES

Symptom Assessment

All patients who were evaluated by the outpatient palliative care program completed the Edmonton System Assessment Scale (ESAS-r) at the initial visit and at a subsequent follow up visit (Appendix B). The ESAS-r if freely available for use, with appropriate acknowledgement of its sources [22, 23].The ESAS-r is a valid and reliable assessment tool of nine common symptoms experienced by cancer patients; (a) pain, (b) fatigue, (c) nausea, (d) depression, (e) anxiety, (d) drowsiness, (e) appetite, (f) well-being, and (g) shortness of breath. The severity at the time of assessment of each symptom is rated from 0 to 10 on a numerical scale; with 0 meaning the symptom is absent and 10 is the worst possibility severity. The ESAS-r has undergone psychometric testing and has good internal reliability (Cronbach alpha 0.68-0.80)[22]. Patients were assigned a numeric number and the pre-treatment and post-treatment scores were recorded on a data collection tool and compared using the Wilcoxon signed-rank test. To evaluate improvements in symptoms, the initial ESAS-r was compared to the follow-up ESAS-r.

Patient satisfaction

Patients had an opportunity to rate level of satisfaction with the care provided by the outpatient palliative care program. Patients accessed the Patient Satisfaction Survey portal developed by Meridian Health (Appendix C) on a computer located in a separate area of the cancer center. The organization’s patient satisfaction survey is freely available for public use and no permission was required for use in the project. The survey was anonymous and voluntary.

Reimbursement

Reimbursement was evaluated by comparing historical billing data from January through March 2017 with the billing during the implementation of the study (April – May 2017). The practice manager provided both billing and reimbursement data. Reimbursements amounts were used to forecast future revenue should the screening process continue.

RESULTS

Clinical and Demographic Characteristics

During the project time-period, 235 eligible patients met screening criteria and 48 patients (20%) were successfully screened. Of the 48 patients screened in the infusion center, 27 were referred to palliative care and received an initial consultation and follow-up visit during the months of April and May. During the same time-period, nine patients were referred by the oncologists. Three patients received an initial and follow-up visit with the palliative care specialist.

All patients had metastatic disease and were receiving chemotherapy. Seventy percent had lung cancer; the remainder had breast, colon, or GI malignancies. There was an even distribution of males and females (20 male and 28 female) and the median age was 70 years (age range 54-90). Nineteen of the new referrals (8%) were new to the cancer center.

Process Measures

Education, Inter-rater Reliability, and Compliance

Of the 20 infusion center staff nurses, all completed the education training for the Five-Item Palliative Care Screening Tool. There was minimal disagreement between infusion nurses scores and the advanced practice nurse scores during the two-week pilot study resulting in a Cohen’s Kappa of 0.74 indicating a relatively high level of agreement. Despite nursing’s support, screening compliance was marginal. Two-hundred patients were eligible for screening; however, only 20% were screened.

Referrals and Reimbursement

During the project period, there were a total of 27 patients seen by the Palliative Care advanced practice nurse as the result of referrals by the infusion center nursing staff and 3 as the result of referrals from the oncology providers. Compared to oncology provider referrals during the same period, 80% more patients were referred by the infusion nurses. The increase in the number of referrals led to significant increases in billing during April 2017 compared to billing from January through March 2017.

Outcome Measures

Symptom Assessment

Thirty patients received a palliative care initial consultation and follow-up visit during the project period. All patients completed a pre and post Edmonton Symptom Assessment. Wilcoxon signed-rank tests were performed to compare differences between patients' pre-intervention ESAS scores and their post-intervention ESAS scores. Statistically significant differences were observed in 6 of the 9 subscales. Results are summarized in Table 1.

Patient Satisfaction

Twenty patients completed the patient satisfaction survey on line immediately after the follow up visit. Results are summarized in Table 2. Patients were generally satisfied with the care provided by outpatient palliative care

DISCUSSION

Outpatient palliative care programs are emerging as an innovative model that seeks to improve the quality of life throughout the continuum of care for patients with serious illness.

However, the volume and timing of referring cancer patients remains a challenge. A lack of a standardized referral criterion has contributed to the gap in referrals. The aim of this quality improvement project was to conduct a process evaluation of an existing outpatient palliative care program and to examine the feasibility of utilizing a palliative care screening tool to identify palliative care needs of cancer patients in an ambulatory infusion center. The infusion nurses were educated on the use of the screening tool and their performance was evaluated to ensure reliability. Assessment of tool inter-rater reliability indicated a relatively high level of agreement. However, compliance utilizing the screening was less than expected. Of the 235 patients eligible for screening, only 48 patients were successfully screened. Nevertheless, screening for palliative care needs in this setting had the potential to significantly improve access, especially when compared to the current standard practice that requires a physician referral. Screening in the ambulatory infusion center resulted in 28% more referrals to palliative care in April and 70% in May compared to referrals from the oncologists. Improving screening compliance among the nursing staff would lead to a higher number of referrals. Incorporating the screening tool into routine nursing work flow would ameliorate this problem.

The improvement in ESAS subscales for pain, tiredness, appetite, depression, anxiety, and well-being demonstrate the utility of palliative care in mitigating common symptoms experienced by patients with metastatic cancer. Palliative care can aid in symptoms management and improve overall well-being. Findings in this study are consistent with other studies that have demonstrated improved patient outcomes in cancer patients with involvement of palliative care.[1, 2,5] Patients were also very satisfied with the service that was provided by palliative care at the cancer center.

The potential for financial improvements was observed as a result of this study. There were substantial increases in reimbursement in April 2017 compared to January, February, and March 2017. However, when May was compared with the historic billing there were no increases in reimbursement. The data suggest there is potential for increased billing and subsequent reimbursement with continued implementation of the screening tool. Compliance with the screening tool would need to be improved to appreciate any potential monetary increase.

LIMITATIONS

There are several noteworthy limitations of this project. First, the study was conducted at a single site making generalizability to other sites or settings difficult. Second, had the project been conducted over a longer time-period, compliance with the screening tool could have been addressed during another pilot cycle. Also, although there were statistically significant decreases in ESAS scores between the first and second palliative care visit, it is uncertain how long improvements would last without ongoing screening. Finally, patients that were not symptomatic or did not have palliative care needs at the time of the screening may have developed symptoms at a later point. Screening one time can consequently result in patients being missed and not referred to palliative care in a timely manner. Ongoing screening for palliative care would reduce the risk of missing patients that may develop symptoms as their disease progresses.

CONCLUSION

Patients with advanced cancer frequently experience a myriad of physical and emotional symptoms throughout the disease trajectory. Symptoms can vary and present at any point during treatment. Identifying the palliative care needs of cancer patients in a timely manner and improving access to outpatient palliative care is imperative. However, timely referral to palliative care remains a salient issue for outpatient palliative care programs. A gap was identified in this author’s healthcare organization which became the impetus for this study. Using a simple tool to identify the palliative care needs of patients with advanced cancer has the potential to increase both access and timely referral to outpatient palliative care. The nurse driven initiative of screening for palliative care needs was proven to be safe, efficient, and equitable in this ambulatory oncology practice. Moreover, making referrals to palliative care based on an assessment of need is within the scope of nursing practice. Further research is necessary to explore nurses' role in the utilization of palliative care screening tools, including methods to improve compliance with the screening and referral process.

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Appendix A

Five-Item Palliative Care Screening Tool

Screening Items	Points
1. Presence of metastatic or locally advanced cancer	2
2. Functional status score, according to ECOG performance status	0-4
3. Presence of one or more serious complications of advanced care usually Associated with a prognosis of <12 months (eg, brain metastases, hypercalcemia, delirium, spinal cord compression, cachexia)	1
4. Presence of one or more serious comorbid diseases also associated with a poor Prognosis (eg, moderate-severe COPD or CHF, dementia, AIDS, end stage renal Failure, end stage liver cirrhosis	1
5. Presence of palliative care problems	
•Symptoms uncontrolled by standard approaches	1
•Moderate to severe distress in patient in family, related to caner Diagnosis or therapy	1
•Patient/family concerns about course of disease and decision making	1
•Patient/family requests palliative care consult	1
•Team needs assistant with complex decision making or determining Goals of care	1
Total	0-13

Abbreviations: CHF, congestive heart failure; COPD, chronic obstructive pulmonary disease; ECOG, Eastern Cooperative Oncology Group

(Glare, P., Semple, D., Stabler, S., & Saltz, L. 2011)

Appendix B

Edmonton Symptom Assessment System Revised:

Please circle the number that best describes how you feel Now:

No Pain	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Pain
No Tiredness	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Tiredness
No Drowsiness	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Drowsiness
No Nausea	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Nausea
No Lack of Appetite	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Lack of Appetite
No Shortness Of Breath	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Shortness of Breath
No Depression Depression	0	1	2	3	4	5	6	7	8	9	10	Worst Possible
No Anxiety	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Anxiety
Best Wellbeing	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Well Being

* Bruera E, Kuehn N, Miller MJ, Selmser P, Macmillan K. The Edmonton Symptom Assessment System (ESAS): a simple method of the assessment of palliative care patients. Journal of Palliative Care 1991; 7:6-9.

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Appendix C

Meridian Care Journey Patient Satisfaction Survey

1. The Palliative Care Provider was respectful and professional				
Strongly Disagree	**Disagree**	**Somewhat Agree**	**Agree**	**Strongly Agree**
2. I was able to talk about my goals and preference for my future care				
Strongly Disagree	**Disagree**	**Somewhat Agree**	**Agree**	**Strongly Agree**
3. The Palliative Care Provider helped me feel more comfortable (i.e. decrease pain, improve nausea				
Strongly Disagree	**Disagree**	**Somewhat Agree**	**Agree**	**Strongly Agree**
4. The Palliative Care Provider helped me coordinate my care				
Strongly Disagree	**Disagree**	**Somewhat Agree**	**Agree**	**Strongly Agree**
5. I am satisfied with the care provided by the Palliative Care Provider				
Strongly Disagree	**Disagree**	**Somewhat Agree**	**Agree**	**Strongly Agree**
***** [a]Adapted with permission from Meridian care journey patient satisfaction survey. Retrieved from https://www.capc.org				

Table 1. Edmonton Symptom Assessment Scale[a,b]
Wilcoxon Signed Rank Test

Symptom	Pre Palliative Care (N=18)	Post Palliative Care (N=18)	Median Difference
Pain	3	1.5	1*

Tiredness	4	2	2*
Drowsiness	0	0	0
Nausea	0	0	0
Appetite	4	2	1.5*
Shortness of Breath	0	0	0
Depression	3	1	2*
Anxiety	4	1	2*
Well-Being	6.5	4	2*

*p<.01

[a] Edmonton Symptom Assessment Scale adapted from Bruera E, Kuehn N, Miller MJ, Selmser P, Macmillan K. Journal of Palliative Care 1991; 7:6-9.

[b] The Edmonton Symptom Assessment System (ESAS) is a simple method of the assessment of palliative care patients. The scale rates severity of symptoms at the time of assessment numerically from 0 (absences of symptoms) to 10 (worst possible severity).

Table 2. Summary Scores: Palliative Care Patient Satisfaction Survey[a] (N=20)

1. The Palliative Care Provider was respectful and professional

Strongly Disagree	Disagree	Somewhat Agree	Agree	Strongly Agree
0%	0%	0%	0%	100%

2. I was able to talk about my goals and preference for my future care

Strongly Disagree	Disagree	Somewhat Agree	Agree	Strongly Agree
0%	0%	0%	0%	100%

3. The Palliative Care Provider helped me feel more comfortable (i.e. decrease pain, improve nausea

Strongly Disagree	Disagree	Somewhat Agree	Agree	Strongly Agree

0%	0%	0%	0%	100%
4. The Palliative Care Provider helped me coordinate my care				
Strongly Disagree	Disagree	Somewhat Agree	Agree	Strongly Agree
0%	0%	0%	20%	80%
5. I am satisfied with the care provided by the Palliative Care Provider				
Strongly Disagree	Disagree	Somewhat Agree	Agree	Strongly Agree
0%	0%	0%	0%	100%

[a] Adapted with permission from Meridian care journey patient satisfaction survey. Retrieved from https://www.capc.org