Published in final edited form as:

J Hosp Palliat Nurs. 2013 October ; 15(7): . doi:10.1097/NJH.0b013e3182a02b9d.

Healthcare Utilization by Patients Whose Care is Managed by a Primary Palliative Care Clinic

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Research related to care at the end of life continues to demonstrate the need for improvement.¹ High rates of hospitalizations and emergency department (ED) visits in the last weeks of life are accepted indicators of poor quality end of life care.²⁻⁴ Despite the desire to avoid ED visits at the end of life and die outside of an institutional setting, the majority of Americans continue to die in healthcare facilities, often with their symptoms poorly managed.^{3,5-7} A lack of primary care providers that are skilled in delivering palliative care, along with the lack of continuity of care, may be contributing to undesired institutional deaths for people at the end of life.³ Common reasons that palliative care recipients are ultimately admitted to an inpatient setting include poor pain control, poor symptom management, an unexpected change in physical condition, and overall caregiver burden.^{8,9} Another contributing factor to hospital admissions can be the general practitioners limited experience in caring for patients dying at home, as well as their limited experience in the use of opioids and psychiatric medications in the setting of a life-limiting illness.⁹

Patients with life limiting illness are not uncommon in the ED. Several studies have investigated ED utilization among patients enrolled in palliative care programs and have reported ranges of 27%^{3,10} up to 39%^{2,11} of patients utilizing the ED near the end of life. In another study, it was noted that elders who died in the ED demonstrated a considerable palliative care need, though the majority of these patients were referred for palliative care services.¹² Researchers identified several determinants of ED use among their palliative care population including excessive weight loss, a previous hospitalization,² women residing in rural areas, having a parent or other relative other than a spouse or child as the primary caregiver,³ pain, and appetite disturbance.¹³ EDs tend to be high stress, fast paced environments with a focus on treatment of acute and traumatic events,¹⁴ and are not the ideal place to treat palliative care patients or those nearing the end of life.^{13,14} For example, privacy in the ED is limited, staff members are often not familiar with patients, nor are they necessarily trained to deal with many issues associated with the end of life.¹⁴ Further, patients and their caregivers experience high levels of anxiety and uncertainty when accessing the ED.

Although circumstances exist where an ED visit or hospital admission may be appropriate at the end of life, certain models of care may reduce unnecessary utilization. For example, palliative care programs have been associated with a reduction in the number of ED visits made by enrolled patients.^{13–16} To illustrate this, in a pilot study by Owens et al. (2012) outpatient primary palliative care patients' mean number of ED visits per week decreased from almost 0.07 visits per week in the earlier period to 0.04 visits per week after enrollment.¹³ Outpatient palliative care is relatively new, and there are limited studies validating its benefits. Outpatient primary palliative care, a setting where palliative care providers also act as primary care providers, is even more unusual. Aside from decreased ED utilization, studies have supported that outpatient palliative care may improve symptom control,^{13, 17–19} improve caregiver and patient satisfaction,^{15, 18, 20} positively affect quality of life,²¹ improve mood,^{16, 21} improve spiritual well being,¹⁹ decrease medical costs,^{7, 15} and at least in the case of non small cell lung cancer, may improve median survival.²²

The primary palliative care practice model differs from an outpatient consultative model in that it seeks to integrate palliative care into primary care. This ensures that palliative needs of patients are routinely addressed in a comprehensive visit from one provider, which also improves continuity of care. The benefits of continuity of care include increased patient and family satisfaction with end-of-life care, reduced ED utilization, increased compliance with treatment recommendations, fewer duplicate diagnostic tests, reduced healthcare costs, and, for some patients, reduced utilization of healthcare services.^{6, 14, 21}

The results of a study by Owens et al. (2012), assessing the relationship between primary palliative care and healthcare utilization, were consistent with previous studies on primary care and continuity of care as it relates to decreased ED utilization,¹³ however, further study was indicated to explore which patient characteristics were associated with ED use. Therefore, the purpose of this study was to further explore the impact of combined primary and palliative care on healthcare utilization by patients with a life-limiting illness. The specific aims were: 1) To explore if emergency department visits and hospital admissions decreased after enrollment into PPSCC, and 2) To describe which patient characteristics were associated with increased use of emergency department and hospital admissions.

Methods

Setting

Harborview Medical Center is a 413 licensed-bed academic medical center, as well as the Northwest region's only Level I adult and pediatric trauma and burn center, located in Seattle, Washington. It is owned by King County, and is one of four hospitals in the UW Medicine Health System. Harborview is the safety net hospital for the county, having provided over \$187 million in charity care in 2010.²³

The Palliative Care Service at Harborview was founded in 2003 by a nurse practitioner as an inpatient consult service. In 2006 the nurse practitioner began collaborating with the Hematology-Oncology clinic to provide outpatient access for patients and assumed responsibility for some of the Hematology-Oncology clinic's complex patients, providing management of pain and other bothersome symptoms. In caring for these patients, it was noted that many of these individuals did not have a primary care provider, and that many frequently utilized the ED for pain and symptom management. These patients were sometimes admitted to the hospital for issues that could have been adequately addressed by an outpatient palliative care specialist.¹³

Based on this need, in 2007 the Primary Palliative and Supportive Care Clinic (PPSCC) was launched with 24-hour access to a palliative care specialist. The mission of the PPSCC is to

provide both primary care and palliative care to patients with life-limiting illness and no primary provider. In addition to oncology patients, the clinic now serves many patients with non-cancer diagnoses including dementia, heart disease, liver disease, kidney disease and lung disease. The clinic also provides services to many patients that experience homelessness, mental illness, active addictive disorders, and incarceration.¹³ Providers are able to see patients in clinic, at home, or at community facilities.

Providers work closely with cultural mediators to provide culturally sensitive care for non-English speaking patients. Patients also have weekday access to a palliative nurse case manager, who plays an important role in addressing and coordinating patient needs. PPSCC currently shares social work services with other hospital based outpatient clinics and does not yet have a full time designated social worker. The team does not have a designated chaplain, but makes use of community and hospital chaplain resources.

PPSCC providers assume the role of both primary care provider and palliative care provider, or act as palliative care consultant. When taking on the role of primary care provider, PPSCC providers assume overall responsibility for the patient's health care including treating acute medical issues, managing chronic illnesses, treating underlying disease processes, and providing preventative health services in addition to addressing palliative needs. If providers are serving only as consultants, the patient has an established primary care provider outside PPSCC.

Study Design and Data Collection

A longitudinal design was used to evaluate the relationship between primary palliative care and healthcare utilization. The study received approval from the University of Washington Internal Review Board. Patient safety risks for this study were minimal as the project involved retrospective data collection only, with no patient contact or care. There was a minimal risk to patient privacy given the collection and use of patients' Protected Health Information.

A purposive sample of all patients receiving their care from the PPSCC during the specified time period, July 1, 2010 through June 30, 2011; there were no other inclusion or exclusion criteria. Two doctoral nursing students and two PPSCC staff members conducted in-depth chart reviews using a data tracking form developed by the PPSCC director. Data extracted included healthcare utilization from the 12-month period prior to the date of enrolling with the PPSCC and utilization from date of enrollment through the date of data extraction. Data was collected from the electronic medical record, which includes inpatient and outpatient records within the UW Medicine system, as well as any outside medical records that may have been scanned into the chart. Records from within the UW Medicine system as well as scanned external records were reviewed closely for ED utilization and hospital admissions both prior to clinic enrollment and after clinic enrollment.

Statistical Analyses

Multivariate descriptive analyses were used to describe relationships between primary palliative care and healthcare utilization, as well as relationships between utilization and various patient characteristics. The distributions of ED visits and hospitalizations were highly skewed. There were few ED visits and hospitalizations for most patients; however, there was a wide range in the number of ED visits made by individual patients, with one patient visiting the ED 33 times during the year prior to enrolling in the clinic. Therefore, a paired t-test approach to testing prior clinic enrollment utilization to utilization after clinic enrollment, while valid, is not as powerful as other available techniques when the distributions are non-normal. Instead, a Generalized Estimating Equations (GEE) model was

used to estimate the relative utilization rate both prior to and after enrollment in the PPSCC. GEE modeling was used since it accounts for intra-individual correlation and accommodates non-normal measures. A GEE model was fit with a log link and variance based on the negative binomial. The negative binomial distribution models highly skewed count data. The relative utilization rate ratio and standard error were estimated using the GEE model and a Wald test was used to test if the ratio was significantly different from 1. This approach was used for both ED visits and hospital admissions.

Results

Demographics

A total of 146 patient records contributed data to the project. Table 1 summarizes the patient characteristics. There were a few more males than females, with an average age of 63.2 years. 57% were Caucasian, 22% Black, 13% Asian, and the remaining reported being of mixed descent or Hispanic ethnicity. Most patients (64%) had a primary diagnosis other than cancer, and represented a variety of life-limiting illnesses including dementia, end-stage kidney disease, chronic obstructive pulmonary disease, dementia, heart failure, and end stage liver disease. Approximately 21% of the patients were cognitively impaired. Two thirds of patients resided in a private home with the others residing at adult family homes, skilled nursing facilities, or were homeless. Half of patients were referred to PPSCC to both assume primary and palliative care, while another third already had an established primary care provider but were referred for palliative care consultation. Hospice was involved in about one third of patients. Medicare (34%) Medicaid (29%) or both Medicare and Medicaid (20%) were the most common payers for services utilized.

Healthcare Utilization

The mean number of ED visits per week decreased significantly after enrollment in the primary palliative care clinic, from mean= 2.46 $\pm$ SD 4.74 to 1.76 $\pm$ SD 3.13, as shown in Table 3. Overall, this represents a 28.6% reduction in ED utilization for subjects once they had established care with the clinic (95%CI: 0.9%–48.5%, $p=0.0437$). There was a wide range in the number of ED visits made by individual patients, with one patient visiting the ED 33 times during the year prior to enrolling in the clinic. The average number of hospital admissions also decreased post-enrollment (pre: mean= 1.28 $\pm$ SD 1.99; post: mean= 1.02 $\pm$ SD 1.44). This represents a 20.2% reduction in hospital admissions (95%CI: -0.7%–36.8%, $p=0.0576$).

Table 2 displays healthcare utilization patterns in the 12 month period prior to clinic enrollment and in the period from the date of enrollment through the date of data abstraction. Utilization data was compared between the two time periods to determine if enrollment in the clinic had any effect on the number of ED visits and hospital admissions. Utilization patterns were broken down and compared between gender, ethnicity, primary diagnosis, residence type, reason for referral and age.

Both males and females showed a decrease in the mean number of ED visits and hospitalizations after enrollment with the PPSCC. On average, males utilized the ED and were hospitalized more than females. Although men utilized healthcare services more than women, men showed a greater reduction in utilization after clinic enrollment, in both ED visits and hospitalizations.

ED and hospital utilization varied by race, with black and Hispanic patients among those with highest mean use. Though ED and hospital utilization was reduced after clinic enrollment for most racial groups, black patients actually saw a slight increase in ED utilization and a small reduction in hospitalizations. Hispanic patients showed a reduction in

ED use after enrollment, but remained among those with the highest utilization rates. Asian patients demonstrated the lowest rates of utilization both before and after enrollment.

Patients with end stage renal disease and non-cancer pain were among the most likely to utilize the ED and be admitted to the hospital prior to clinic enrollment. These patients saw very little in the reduction in utilization after clinic enrollment. In contrast, patients with dementia were among the least likely to use the ED, and saw an even further reduction in ED utilization after enrollment in the clinic. All other diagnoses saw some reduction in ED utilization and hospital admission.

There was some variation in utilization of ED and hospital admissions based on place of residence. Those residing in adult family homes and skilled nursing facilities demonstrated a significant reduction in the ED usage and hospital admissions after enrollment. Though patients experiencing homelessness represented a minority of the clinic population (N=7), they had very high mean utilization rate prior to establishing care, and saw this rate largely reduced. Those living in a private home or apartment alone or with family showed no reduction in ED or hospital utilization. Even so, ED use rates for those living in private homes remained well below those patients experiencing homelessness.

At baseline those patients that were referred as palliative consults or for management of non-cancer pain were more likely to utilize the ED and be admitted to the hospital than those referred to establish primary palliative care. After clinic enrollment ED utilization rates were similar for both those referred for primary palliative care and for those referred as a consult, while hospital admission rates for these two groups were nearly identical after enrollment. Again, those referred for palliative consults had established primary care providers outside PPSCC, so were still receiving primary care from an outside source. Those referred for management of non-cancer pain showed little reduction in ED use or hospital admissions after enrollment, which is consistent with data related to primary diagnosis above.

At baseline patients between the ages of 29–48 used the ED the most often and patients ages 39–48 had the most hospital admissions. These age groups demonstrated a significant decrease in their ED use and hospital admissions after clinic enrollment, but remained among those with the highest healthcare utilization. Patients age 49–68 saw very little change in the number of ED visits and hospital admissions after clinic enrollment, but were still well below rates of use for the 29–48 age group. The most elderly patients, age 89–98, represented those least likely to use the ED and be admitted to the hospital both before and after clinic enrollment.

Discussion

This project provides additional evidence that a nurse practitioner founded and directed outpatient primary and palliative care clinic can reduce healthcare utilization at the end of life. The results of this project are consistent with the previous work, and with other prior studies on primary care and continuity care as it relates to decreased ED utilization.^{6,13} The reduction of ED utilization and management of palliative care needs on an outpatient basis represents a potential improvement in both quality of life and quality of death. This also suggests the importance of early and improved access to outpatient primary and palliative care. Indirectly, these findings support reduced costs associated with caring for patients, specifically through reduction of ED utilization and hospital admissions.

Based on the results of this project, we can see some groups of patients were impacted more than others. It may be that some patients are well served by the existing primary palliative care clinic model, while other patients may benefit from modification of the clinic model or additional support to ensure their needs are being met. For instance, patients with dementia,

chronic heart failure, chronic obstructive pulmonary disease and other non-cancer diagnoses did very well with this current clinic model, while an alternate model may better serve patients with end stage renal disease and chronic non-cancer pain. Black patients stand out as the only racial group that did not see a decrease in ED utilization. Further investigation is warranted in exploring whether the needs of black patients are being addressed within this clinic model, or whether an additional concurrent factor, such as disease process or socioeconomic variables, affected outcomes. Finally, patients living in private homes, many of who live alone would benefit from additional investigation and perhaps an additional layer of resources, as their lack of significant decrease in ED utilization may reflect the need for additional support at home.

Limitations

The length of time that the patients were followed varied, which had a likely effect on utilization data. Data was collected from date of first clinic visit through date of abstraction, which ranged from less than six months to over three years. Another limitation of the study is the possibility that patients may have presented to another local ED outside of the hospital's electronic medical record network, and that the outside ED may not have forwarded all instances of ED utilization to PPSCC. Further, the data collected did not capture whether an ED visit or hospital admission was related to an unmet palliative care need.

There was no control group for comparison, though given the nature of the population under study, identifying a control group would present a challenge. Calculations do reflect the same group of patients before and after clinic enrollment. Further research including a comparison group would be warranted. A potential control group could be sampled from Medicare data pertaining to patient characteristics and utilization statistics of the general population of the same county as the site of data collection, King County, Washington in the setting of this study. One other possible weakness is that HMC is a large, urban county hospital serving a diverse population and there is a possibility that results may not be generalized to other types of settings.

Conclusion

This study is consistent with evidence showing that palliative care patients often utilize healthcare resources, such as the ED, for management of their needs.^{3,6,10,11,14} The findings also demonstrate that combined outpatient primary and palliative care decrease ED utilization and hospital admissions in patients with life limiting illness. Given the imminent changes to the United States healthcare system, including the establishment of accountable-care organizations charged with reducing ED utilization and hospital admissions, the dissemination of this study could have a significant impact on decreasing unnecessary healthcare utilization across the country. Further study is recommended to address cultural needs and barriers of racial groups that demonstrate high utilization, to investigate how to better serve patients living with end stage renal disease and non cancer pain, and to further discern factors that may be impacting patients living in private homes.

Acknowledgments

Funding for this project was provided to the Outpatient Primary Palliative and Supportive Care Clinic at Harborview Medical Center by the Cambia Foundation. Ardith Doorenbos's time on this project was partially funded by National Institute of Nursing Research grant # R01NR012450.

We also acknowledge Donna McArthur, PhD, RN and Richard Watters, PhD, RN both of Vanderbilt University School of Nursing as doctoral committee members for author Murphy during this project; Hilaire Thompson, PhD, RN, of University of Washington School of Nursing as doctoral committee member for author Siebert during this

project; and Amber Robbins, BSN, RN Case Manager of Outpatient Palliative and Supportive Care Service, Harborview Medical Center for her assistance in data collection.

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Table 1**Patient Characteristics**

Patient characteristics	N (%)
Gender	
Men	78 (53%)
Women	68 (47%)
Ethnicity	
Caucasian	83 (57%)
Hispanic	5 (3%)
Asian	19 (13%)
Black	32 (22%)
Mixed	4 (3%)
Unknown	3 (2%)
Primary life limiting diagnosis	
Cancer/Cancer Pain	51 (36%)
ESRD/Non Cancer Pain	39 (27%)
Dementia, cognitive impairment	19 (13%)
Cardio/Pulmonary	15 (11%)
Other	19 (13%)
Unknown	3 (2%)
Cognitively intact patient	
Yes	104 (71%)
No	30 (21%)
Unknown	12 (8%)
Primary place of residence	
Private home	94 (64%)
Adult family home	16 (11%)
Skilled nursing facility	22 (15%)
Assisted living facility	4 (3%)
Homeless/shelter	7 (5%)
Unknown	3 (2%)
Reason for referral	
Assume primary palliative care	69 (47%)
Consult	43 (29%)
Nonmalignant pain	24 (17%)
Unknown	10 (7%)
Insurance payer	
Medicare	49 (34%)
Medicaid	43 (29%)
Both	29 (20%)
Other	25 (17%)
Hospice involved	50 (34%)

Patient characteristics	N (%)
Age	
18–28	3 (2%)
29–38	6 (4%)
39–48	11 (7%)
49–58	46 (32%)
59–68	31 (21%)
69–78	19 (13%)
79–88	13 (9%)
89–98	17 (12%)
Age	Mean (Range)
	63.2 (21–97)

Table 2**ED Utilization and Hospital Admissions Pre and Post Clinic Enrollment**

	Pre Enrollment ED Utilization Mean (SD)	Post Enrollment ED Utilization Mean (SD)	Pre Enrollment Hospital Admissions Mean (SD)	Post Enrollment Hospital Admissions Mean (SD)
Gender				
Men	3.29 (5.97)	2.27 (3.79)	1.64 (2.43)	1.19 (1.61)
Women	1.50 (2.37)	1.18 (2.02)	0.88 (1.19)	0.84 (1.20)
Ethnicity				
Caucasian	2.39 (5.40)	1.25 (1.67)	1.31 (2.27)	0.99 (1.24)
Hispanic	5.50 (7.77)	3.00 (2.24)	1.80 (1.79)	1.60 (0.89)
Asian	1.10 (1.76)	0.68 (1.25)	0.53 (0.61)	0.37 (0.68)
Black	3.41 (3.87)	3.72 (5.57)	1.78 (1.83)	1.53 (2.12)
Mixed	0.75 (0.95)	0.75 (0.95)	0.50 (0.58)	0.50 (0.58)
Primary diagnosis				
Cancer/Cancer Pain	2.02 (2.88)	1.59 (2.13)	1.10 (1.04)	0.82 (0.91)
ESRD/Non Cancer Pain	3.22 (5.90)	2.95 (4.22)	1.85 (2.96)	1.72 (1.81)
Dementia/cognitive impairment	0.74 (1.63)	0.26 (0.56)	0.32 (0.48)	0.05 (0.23)
Cardio/Pulmonary	3.57 (4.50)	2.01 (4.75)	1.80 (2.40)	1.47 (2.10)
Other	2.84 (7.51)	1.21 (2.18)	1.05 (1.47)	0.89 (1.29)
Primary place of residence				
Private home	1.86 (2.71)	1.94 (3.60)	1.11 (1.55)	1.04 (1.44)
Adult family home	1.56 (3.67)	0.50 (0.73)	0.38 (0.81)	0.25 (0.58)
Skilled nursing facility	3.50 (6.84)	1.36 (2.22)	2.36 (3.33)	1.18 (1.79)
Assisted living facility	0 (0)	1.75 (1.71)	0 (0)	1.25 (1.50)
Homeless/shelter	9.43 (11.73)	3.43 (2.57)	2.15 (1.95)	1.57 (1.27)
Reason for referral				
Assume primary palliative care	1.78 (2.92)	1.55 (3.02)	0.97 (1.47)	0.81 (1.31)
Consult	3.00 (5.76)	1.34 (1.90)	1.28 (1.30)	0.83 (1.02)
Non-cancer pain	3.67 (6.85)	3.17 (4.90)	2.04 (3.56)	1.95 (2.05)
Age				
18–28	1.33 (2.31)	1.33 (1.53)	1.00 (1.73)	1.33 (1.53)
29–38	6.50 (13.00)	2.83 (6.00)	1.83 (2.23)	1.33 (1.75)
39–48	7.55 (9.26)	3.27 (5.83)	4.27 (4.69)	2.00 (2.79)
49–58	1.93 (3.27)	1.78 (2.01)	1.09 (1.24)	1.26 (1.06)
59–68	2.32 (3.17)	2.42 (4.51)	1.29 (1.42)	1.13 (1.52)
69–78	2.11 (3.02)	1.26 (2.23)	1.26 (1.76)	0.53 (.070)
79–88	2.08 (2.10)	1.15 (1.86)	0.85 (0.69)	0.85 (1.77)
89–98	0.13 (0.50)	0.24 (0.56)	0.12 (0.33)	0.12 (0.49)

Table 3

Overall Utilization Patterns Pre and Post Clinic Enrollment

	Pre Enrollment ED Utilization	Post Enrollment ED Utilization	Pre Enrollment Hospital Admissions	Post Enrollment Hospital Admissions
Total Visits	352	257	188	150
Mean (SD)	2.46 (4.74)	1.76 (3.13)	1.29 (1.99)	1.03 (1.44)
Median (Range)	1 (0, 33)	1 (0, 22)	1 (0, 15)	1 (0, 8)