

HHS Public Access

Author manuscript *J Hosp Palliat Nurs*. Author manuscript; available in PMC 2024 July 30.

Published in final edited form as:

J Hosp Palliat Nurs. 2022 June 01; 24(3): 167–174. doi:10.1097/NJH.00000000000845.

Hospice Referral in Advanced Cancer in New Jersey

Bridget L. Nicholson, PhD, APRN, AOCNP, ACHPN,

Rutgers School of Nursing, Rutgers, The State University of New Jersey, New Brunswick.

Linda Flynn, PhD, RN, FAAN [dean], Rutgers School of Nursing, Rutgers, The State University of New Jersey, New Brunswick.

Beth Savage, PhD, CPNP, CPON [assistant professor], Rutgers School of Nursing, Rutgers, The State University of New Jersey, New Brunswick.

Peijia Zha, PhD [assistant professor], Rutgers School of Nursing, Rutgers, The State University of New Jersey, New Brunswick.

Elissa Kozlov, PhD [instructor]

Rutgers School of Public Health, Rutgers, The State University of New Jersey, New Brunswick.

Abstract

The need for hospice care is increasing in the United States, but insufficient lengths of stay and disparity in access to care continue. Few studies have examined the relationship between the presence of symptoms and hospice referral. The study measured the association between hospice referral and demographic characteristics and the presence of pain and depression in a cohort of people hospitalized with metastatic cancer in New Jersey in 2018. This study was secondary analysis of the 2018 New Jersey State Inpatient Database. The sample was limited to adult patients with metastatic cancer. Descriptive statistics evaluated the composition of the sample. Generalized linear modeling estimated the effect of pain and depression on incidence of hospice referral in a racially and economically diverse population. Absence of pain resulted in lower odds of receiving a referral to hospice upon discharge (adjusted odds ratio [AOR], 0.44; 95% confidence interval [CI], 0.40-0.49; P = .00). Likewise, an absence of depression also resulted in decreased odds of a hospice referral (AOR, 0.85; 95% CI, 0.76-0.96; P = .008). Compared with Whites, Blacks (AOR, 0.86; 95% CI, 0.76-0.97; P = .00) and Hispanics had significantly lower odds of receiving a hospice referral (AOR, 0.84; 95% CI, 0.72-0.96; P = .01). Patients with a primary language other than English, there were significantly lower odds of receiving a hospice referral (AOR, 0.85; 95% CI, 0.73-0.99; P = .03). Patients with pain and depression had increased hospice referrals. Disparities persist in hospice referral, particularly in Black and Hispanic cases and those without a primary language of English.

Keywords

depression; hospice; pain; primary language; racial disparities

Address correspondence to Bridget L. Nicholson, PhD, APRN, AOCNP, ACHPN, Rutgers, The State University of New Jersey, 110 Patterson St. New Brunswick, NJ 08901 (nicholbl@sn.rutgers.edu).

Hospice is a philosophy of care that focuses on symptomatic care of patients with advanced illness.¹ The hospice philosophy is the provision of care transitions from life-sustaining treatment to comfort and symptomatic relief. Hospice use is a quality end-of-life indicator recommended by the Institute of Medicine.² Delivery of care is performed by registered nurses, physicians, clergy, home health aide, physical therapy, and, less often, psychologists. Hospice care occurs in the community in homes, outpatient facilities, and the acute care setting.

Metastatic cancer patients typically have a predictable trajectory, including a decline before a "terminal phase," allowing time to consider end-of-life planning.² Patients with a diagnosis of metastatic cancer, or cancer beyond the original site of disease, are eligible for hospice when predicted to have less than 6 months to live.¹ In 2017, 50.7% of Medicare decedents received hospice for 1 or more days.¹ This number represents a steady increase since 2014.¹ Patients with a diagnosis of advanced cancer comprise most patients on hospice across the country; however, the lengths of stay on hospice remain short. Twenty-eight percent of patients still have a length of stay less than 7 days, and 54% had a length of stay less than 30 days.¹ Short lengths of stay limit patients must have a referral and accept care. Referral can occur during hospitalization or from the community setting. This study examines referral from the inpatient setting, because inpatient hospitalization can be a trigger for hospice referral.

Multiple demographic factors have been shown to impact the receipt of hospice care.^{3,4} For example, the literature has consistently demonstrated older aged^{4,5} and female patients⁵ were more likely to use hospice care. Furthermore, higher income has been shown to increase hospice service use.^{3,5}

Racial minorities have decreased use of hospice care.³ Karikari-Martin et al³ examined the outcome of hospice use and found, in all diagnoses, African Americans were almost half as likely to use hospice compared with Whites. A more recent study found Hispanics were more likely to be discharged to hospice compared with non-Hispanic Whites in an urban sample of hospitals.⁶ Overall, challenges exist to provide equal access to hospice care for racial minority groups.

Primary language spoken may be a barrier to receipt of hospice care. Few studies have assessed primary language of English and its relationship to hospice care.⁷ Park et al⁷ documented English proficiency increased willingness to participate in hospice care. Because one-quarter of Americans speak a language other than English at home and 8.4% of Americans have limited English language proficiency,⁸ it is important to have a better understanding of this potential barrier to hospice.

The ability to access hospice care may also be influenced by insurance status and the geographic region of the United States. Insurance status allows patients access to care. Medicare patients are most likely to receive hospice care across diagnoses⁹ (compared with other insurances). Nationally, there is variation in utilization rates across geographic regions.^{1,10} Sheu et al¹¹ found that patients in the South and West were more likely to die

in hospice care compared with those in the Northeast. New Jersey in particular ranks 39th in hospice utilization. $^{\rm 1}$

Often, pain and depression are known to be present in patients with advanced cancer,^{12,13} but the relationship between the clinical symptoms and hospice referral is not fully understood. Karikari-Martin et al³ found worsening health status to be associated with hospice use but did not examine specific diagnoses. McDermott et al¹³ found hospice referral is more likely in patients with a preexisting diagnosis of depression. Furthermore, Adjei Boakye et al¹⁴ found rates of depression in metastatic cancer patients may be increasing over time, and racial minority patients were less likely to be given a diagnosis of depression than Whites.^{14,15} This suggests there may be a disparity in the recognition of symptoms potentially influencing referral patterns.

The purpose of this study was to examine the relationship among demographics, symptoms of pain and depression, and hospice referral. We hypothesized that patients with a diagnosis of pain and depression would have an increased likelihood of hospice referral but that demographic factors such as age, sex, race, income quartile, primary language, and insurance status may also impact receipt of care.

METHODS

Conceptual Framework

The synthesis of the Theory of Healthcare Utilization and the Theory of Unpleasant Symptoms was used to describe factors that predict use of health care resources, in this case, hospice referral.^{16,17} The Theory of Health Care Utilization proposes that a combination of predisposing factors (eg, age, race, income quartile by zip code, sex, and primary language), enabling factors (eg, payer source), and need factors (eg, pain and depression) will predict hospice referral.¹⁶ The Theory of Unpleasant Symptoms describes need factors to include concurrent and multiple discomforting symptoms, which are synergistic in nature and may predict health care services use, including hospice care.¹⁷

Sample

The Health Care Utilization Project (HCUP) New Jersey state inpatient database (SID) is a census of the hospitalizations for the year.¹⁸ The 2018 database is composed of data from 70 inpatient facilities. Each case contains up to 30 *International Classification of Diseases, Tenth Revision, Clinical Modification* (ICD-10-CM) format codes.¹⁹ The original sample contained 917 250 cases. In this study, the New Jersey sample was limited to patients with a diagnosis of metastatic cancer. Metastatic or advanced cancer is defined as cancer spread beyond its original site of disease.²⁰ This delimitation was performed by ICD-10-CM diagnoses of C77.x, C78.x, and C79.x. This yielded 28 697 cases.

To initiate hospice service in New Jersey, a referral must be present. The 2018 NJ HCUP SID database provides a variable to indicate discharge status reflecting this referral process. Any case in which the discharge status was indicated to be either "home hospice" or "hospice facility" was considered as an indication that hospice referral was initiated. Referral in this study means that the patient was discharged with the intent of initiating

hospice. However, the available data did not allow tracking of care received or death on hospice.

Demographic factors examined in this study include age, sex, partnered status, income status, primary language, primary payer source, and race. Age, sex, income quartile, primary payer source, and race were available in the database. The language variable in the database was dichotomized to those identified with a primary language of English and those who identified as speaking a primary language other than English. The partnered status variable was dichotomized to partnered or not partnered. Pain and depression were operationalized using ICD-10-CM codes and recoded to serve as indicators of the presence of the symptom based on the presence of ICD-10-CM codes. Pain was indicated by the presence of the ICD-10-CM codes for depression codes included major, situation, endogenous, and adjustment disorder (F06.3, F32.x, F33.x, F34.x, and F43.x, respectively).

STATISTICAL ANALYSES

The researcher inspected and cleaned the data. A rate of less than 5% missing data was considered acceptable, and all factors examined met this condition.²¹ Data were examined for descriptive frequencies of the sample. An independent sample *t* test was conducted to examine the age difference between cases that did and did not receive hospice care. Chi-squared Tests were performed to investigate associations between predisposing, enabling, and need factors and inpatient palliative care consultation. Generalized linear models, or binary logistic regression models, examined the relationship between the predisposing, enabling, and need factors and hospice referral. Only significant variables determined through χ^2 testing were included in a final model for hospice referral. Significance was set at *P*<.05. Statistical analysis was performed in SPSS 27.

RESULTS

The NJ SID 2018 sample contained 28 697 cases with a diagnosis of metastatic cancer. Full demographic statistics can be visualized in Table 1. Of these cases, 3279 (11.4%) received a hospice referral upon discharge. The sample was slightly more female (n = 15 093, 52.6%) than male. The average age of the sample was 67.16 (SD, 13.8) years. The sample was predominantly White (n = 18 661, 65.6%), followed by Black (n = 4395, 15.3%), Hispanic (n = 3272, 11.5%), Asian or Pacific Island (n = 1058, 3.7), American Indian (n = 27, 0.1%), and Other (n = 1015, 3.5%). Most of the sample was in the highest median income bracket of greater than \$79 000 per zip code (n = 14 931, 52%), followed by the \$59 000-to-\$78 999 category (n = 6445, 22.5%), \$46 000-to-\$58 999 category (n = 3661, 12.8%), and \$1-to-\$45 999 category (n = 3495, 12.2%). Medicare was the primary payer for most cases (n = 16 236, 56.6%). Those who were referred to hospice were significantly older (mean [SD], 70.68 [13.10]) than patients who were not referred (mean [SD], 66.71 [13.86]) ($t_{28 695} = -15.53$, P < .001).

This study found increased hospice referral was associated with older age groups, $\chi^2(4, n = 28\ 697) = 248.23$, *P*<.001. There were significant differences between racial groups

and a referral to hospice, $\chi^2(4, n = 28 \ 428) = 52.43$, P < .001. Whites received the most hospice referrals (12.4%), followed by Blacks (9.9%), Hispanics (9.7%), Asians or Pacific Island (9.7%), and Other (9.1%). The rate of hospice referral was higher in cases in which the patient reported speaking English as their primary language compared with those with another primary language, $\chi^2(1, N = 28 \ 697) = 19.23$, P = .00. There were significant differences between median household income on hospice referral, $\chi^2(3, N = 28 \ 532) =$ 31.21, P < .001. Medicare as the primary payer source had a significant relationship with hospice referral, $\chi^2(5, N = 28 \ 697) = 120.77$, P < .001. Pain was significantly associated with hospice referral, $\chi^2(1, n = 28 \ 697) = 175.88$, P < .001. Of hospice referral cases, 19.2% had a diagnosis of pain compared with 10.6% who did not. The presence of a depression diagnosis was significantly associated with hospice referral, $\chi^2(1, n = 28 \ 697) = 11.40$, P < .001. Moreover, cases with both diagnoses of pain and depression were significantly associated with hospice referral, $\chi^2(1, n = 28 \ 697) = 21.58$, P < .001. These results are demonstrated in Table 1.

The variables included in the adjusted model included age, income, race, primary language, payer source, pain, and depression. The final Omnibus model demonstrated significance when compared with the null model, $\chi^2(17, N = 28\ 267) = 492.02$, degrees of freedom (*df*), P < .001. These results are found in Table 2. Younger age was negatively associated with the likelihood of hospice referral compared with the oldest age category (P < .001). The category of \$59 000 to \$78 999 demonstrated increased odds of hospice referral (adjusted odds ratio [AOR], 1.14; 95% confidence interval [CI], 1.04-1.25; P=.005). Compared with Whites, Blacks had decreased odds of hospice referral (AOR, 0.86; 95% CI, 0.76-0.97; P = .00), as did Hispanics had (AOR, 0.84; 95% CI, 0.72-0.96; P = .01). Cases identified as having a primary language other than English had lower odds of hospice referral (AOR, 0.85; 95% CI, 0.73-0.99; P = .03). Both Medicaid payers (AOR, 0.83; 95% CI, 0.70-0.98; P = .03) and private insurance payers (AOR, 0.86; 95% CI, 0.77-0.97; P = .01) had lower odds of receiving a hospice referral than Medicare payers. Those cases without a pain diagnosis had lower odds of receiving a referral (AOR, 0.44; 95% CI, 0.40-0.49; P = .00). Cases without a diagnosis of depression also had lower odds of a hospice referral (AOR, 0.85; 95% CI, 0.76-0.96; *P*= .008). Results are listed in Table 2.

DISCUSSION

This study demonstrated that multiple clinical and demographic factors predicted hospice use. Cases in which race was designated as Black or Hispanic cases and those cases indicating the primary language other than English were less likely to receive a hospice referral. Cases with older age at hospitalization and Medicare as a payment source were more likely to have a hospice referral. Compared with the highest median income level, the second highest was most likely to have a hospice referral. The presence of pain and depression both strongly predicted hospice referral.

The goal of hospice referral is to provide information on the hospice benefit and provide care when the patient is ready to receive care. This study supports previous literature that older age leads to increased hospice utilization.³⁻⁵ However, there must be appropriate access to hospice referral for patients of all ages with metastatic cancer. Income disparities

persist. This study shows an increased referral rate in the higher middle-income categories. Within this study, the highest and lowest income categories had the same likelihood of hospice referral. Notably, cases in the income category of \$46 000 to \$58 999 had decreased likelihood of referral, whereas those in the income category of \$58 999 to \$79 000 had greater likelihood of referral. Further research should investigate whether patients in the low middle-income category have decreased resources preventing patients and families from obtaining hospice referrals. These findings contradict previous literature where the highest income categories receive the greatest amount of hospice care.⁵ More research is needed to understand the relationship between income status and hospice referral.

This study found cases who identified as not speaking English as their primary language had decreased odds of hospice care. Cases with a nonprimary English language in the home had 15% lower hospice referrals than English speakers. A previous study indicated that patients with limited English proficiency were less likely to elect hospice care.⁷ End-of-life conversations are complex and require language proficiency. There are documented barriers to the translation of the concept of hospice in the Spanish language. The direct translation of hospice is documented to have a negative connotation of "poorhouse or orphanage."²² This translation may provide an initial care barrier to Spanish speakers.²² Spanish is the most common language behind English in the United States.⁸ Other barriers to implementing care include the underutilization of translation services for patients who do not identify as primary English speakers.²³ Providing inadequate resources to patients with limited English proficiency may worsen disparities, including decreased hospice referral. More research is needed to understand current clinical practice patterns and their impact on hospice referral and utilization outcomes.

This study confirms racial disparities persist in hospice referral patterns. Blacks were 15% less likely and Hispanics were 16% less likely to receive hospice referrals in New Jersey hospitals compared with Whites. Ultimately, there are factors in hospice referral among racial groups that remain poorly understood. Health literacy and knowledge of programing impact hospice use. Shreenivas et al²⁴ found that patients from minority backgrounds were more likely to prefer palliative care compared with hospice and have misconceptions regarding hospice care, including a perception of increased cost. Additional studies report barriers to hospice care in Hispanics included language, discrimination, and perceived cost of care.²² This study suggests that recent efforts to address knowledge barriers have not impacted care patterns. Future work is necessary to evaluate obstacles to care and gaps in coverage as they impact acceptance of hospice referral.

This study confirmed previous findings that Medicare recipients were most likely to receive a hospice referral.²⁵ This finding may be impacted by Medicare services set guidelines for hospice care. There remains a need to educate both clinicians and patients on the hospice benefit for all beneficiaries.

This study demonstrated clinical factors impact hospice referral patterns. Patients with a diagnosis of pain were significantly more likely to receive a hospice referral. Depressed patients were 14% more likely to receive hospice referrals. Patients with advanced metastatic disease have multiple burdensome symptoms, which may impact health care

services utilization. Screening for depression in metastatic cancer patients before hospice referral is variable.²⁶ This concern is compounded by decreased detection and treatment of psychiatric symptoms across racial groups in patients with metastatic cancer at the end of life.^{14,15,27,28}

Pain and depression are need factors that impact total patient suffering and utilization of care. Pain and depression both have validated scales to measure the occurrence of the symptom and response to an intervention. Pain scales are commonly used in both the palliative care and hospice practice environments. The "Clinical Practice Guidelines for Quality Palliative Care" states physical and psychological symptoms should be assessed with validated symptom assessment scales.²⁹ Although the guidelines support screening for depression, there remains a lack of uniformity across practice environments. Access to mental health and psychiatric resources for patients remains limited. Furthermore, patients may have difficulty navigating the available resources for depression, Depression may impact patient care utilization, including the use of hospice. As such, further research must evaluate both screening patterns and patients' ability to access care.

LIMITATIONS

This study has several limitations. Secondary analyses are limited by the data points collected and the rigor of the original data procurement. The data analyzed in this study were collected by New Jersey inpatient facilities, submitted to the Agency for Health Research and Quality. The data are maintained by the Agency for Health Research and Quality and available for research use.¹⁸ Because of the collection process, the ability to obtain additional data points that may impact the dependent variable is limited.

In addition, as discussed previously, the outcome of hospice referral is unable to quantify the amount of hospice care delivered or whether care was declined after discharge from the acute setting. Patients may decline hospice care after the initial discharge, as previously collected data in this study were not able to quantify those results. Barriers and facilitators to hospice referral can include both patient and oncologist factors. Although this study focuses on the demographic and symptom factors, it is unable to add information on patients who did not receive referrals because of oncologist hesitancy to provide a referral. Ultimately, hospice referral relies on the combination of perceived need and readiness by the patient and the evaluated need of the oncologist or attending.

The use of provider billing codes is another limitation in this study. These codes may underdetect the symptomatic incidence occurrence but have been found to have moderate accuracy.³⁰ The use of ICD-10-CM codes for pain and depression may have led to underdetection of both pain and depression. In addition, patients may have subclinical depressive symptoms that may be underdetected in practice.

A further limitation is the compilation of all data into 1 record. This does not allow analysis of provider- and institution-specific policies and procedures surrounding protocols for hospice referral. Likewise, administrative data sources, such as HCUP, use billing codes but do not consider the other practice standards of an institution that potentially influence

outcomes. Within this study, factors that cannot be accounted for include information regarding disease treatment, response to therapy, or previous use of palliative care services.

The use of the New Jersey data set may limit generalizability to other regions. In future studies, a national database would provide access to information on regional differences in providing hospice referral and differences between regional populations.

IMPLICATIONS

Despite efforts to reduce disparities in hospice use, inequities remain. Nurses comprise the majority of the hospice and palliative care workforce and thus have a deep understanding of hospice referral processes and both patient and provider barriers to care. Nurses are also in a unique position to detect patient need factors, including symptomatic needs. Validating current and developing new screening tools to identify need factors across demographics is necessary. Implementing the consistent use of these tools in clinical practice may help decrease disparities in care patterns. After the identification of need factors, resources must be available to address both physiologic and psychological symptoms. Research is needed to more adequately deliver psychological services to patients with metastatic cancer.

These study findings highlight the continued differences in referral to hospice care. Previous work has reported that demographic characteristics and clinical factors contribute to patient engagement in health care behaviors at the end of life, yet transforming inequities into substantial changes has been slow to fruition. Nurses may be able to reduce disparities through uniform recognition of clinical need factors. Further understanding of referral patterns will allow directed education programs to improve clinician and patient understanding of available resources. Improved access to services must be provided to reduce the total suffering burden in patients with metastatic cancer.

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TABLE 1

Descriptive Hospice Referral Statistics

Variable	Total N (%)	Hospice Absent, n (%)	Hospice Present, n (%)	Siga
Age, y				00.
<50	2547 (8.9)	2361 (92.7)	186 (7.3)	
50-64	8807 (30.7)	7988 (90.7)	819(9.3)	
65-74	8505 (29.6)	7563 (88.9)	942 (11.1)	
75-84	6159 (21.5)	5327 (86.5)	832 (13.5)	
85	2679 (9.3)	2179 (81.3)	500 (18.7)	
Race				.00
White	18 661 (65.6)	16 348 (87.6)	2313 (12.4)	
Black	4395 (15.5)	3960 (90.1)	435 (9.9)	
Hispanic	3272 (11.5)	2972 (90.3)	300 (9.7)	
Asian	1058 (3.7)	955 (90.3)	103 (9.7)	
Other	1042 (3.7)	947 (90.9)	95 (9.1)	
Sex				.11
Male	13 604 (47.4)	12 092 (88.9)	1512 (11.1)	
Female	15 093 (52.6)	13 326 (88.3)	1767 (111.7)	
Payer				.00
Medicare	16 236 (56.6)	14 092 (86.8)	2144 (13.2)	
Medicaid	2732 (9.5)	2503 (91.6)	229 (8.4)	
Private	8303 (28.9)	7526 (90.6)	777 (9.4)	
Other	1426 (5.0)	1297 (91.0)	129 (9.0)	
Median income, \$.00
1-45 999	3494 (12.2)	3134 (89.7)	361 (12.2)	
46 000-58 999	3661 (12.8)	3307 (90.3)	354 (9.7)	
59 000-78 999	6445 (22.6)	5642 (87.5)	803 (12.5)	
>79 000	14 931(52.3)	13 194 (88.4)	1737 (11.6)	
Partnered				.06

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ssion 28 264 (98.5) 25 065 (88.7) 433 (1.5) 353 (81.5)	Depression	3127 (10.9)	2865 (87.4)	414 (12.6)	
ion 28 264 (98.5) 25 065 (88.7) 433 (1.5) 353 (81.5)	Pain + depression				00 [.]
433 (1.5) 353 (81.5)	No pain + depression	28 264 (98.5)	25 065 (88.7)	3199 (11.3)	
	Pain + depression	433 (1.5)	353 (81.5)	80 (18.5)	

Abbreviation: Sig, significance.

^{*a*}Significance determined by χ^2 testing.

TABLE 2

Final Hospice Model

	В	SE	AOR	Sig	AOR LLCI	AOR ULCI
Omnibus test	492.02 (<i>df</i> = 17)			00.		
Age (ref: 85+), y						
<50	-1.03	0.10	0.36	.00	0.29	0.44
50-64	-0.76	0.07	0.47	00.	0.40	0.54
65-79	-0.63	0.06	0.54	.00	0.47	09.0
75-84	-0.40	0.06	0.67	.00	0.59	0.76
Income (ref: >\$79 000)						
1-45 999	0.05	0.07	1.05	.44	0.92	1.20
46 000-58 999	-0.09	0.06	0.91	.14		1.03
59 000-78 999	0.13	0.05	1.14	.01	1.04	1.25
Language (ref: English as primary language)	-0.17	0.08	0.85	.03	0.78	66.0
Race (ref: White)						
Other	-0.18	0.11	0.83	.11	0.66	1.04
Asian	-0.06	0.11	0.94	.56	0.76	1.16
Hispanic	-0.18	0.07	0.84	.01	0.72	96.0
Black	-0.15	0.06	0.86	.01	0.76	26.0
Payer						
Other	-0.08	0.10	0.93	.48	0.75	1.14
Private insurance	-0.15	0.06	0.86	.01	0.77	26.0
Medicaid	-0.19	0.08	0.83	.03	0.70	86.0
Pain (ref: pain)	-0.82	0.05	0.44	00.	0.40	0.49
Depression (ref: depression)	-0.15	0.06	0.86	.01	0.73	0.99

J Hosp Palliat Nurs. Author manuscript; available in PMC 2024 July 30.

Abbreviations: AOR, adjusted odds ratio; LLCI, lower level confidence interval; Sig, significance; ULCI, upper level confidence interval.