Palliative Care Consults in U.S. Nursing Homes: Not Just for the Dying

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Abstract

Background: Little is known about nursing home (NH) residents who receive palliative care (PC) consults in the United States.

Objective: Separately by short versus long (≥ 90 days) stays, to describe NH residents with PC consults compared to a prevalent NH sample.

Design: Descriptive longitudinal study.

Setting/Subjects: NH residents in 2008–2010 in 54 NHs.

Measurements: Resident characteristics came from merged Medicare and NH data from the Centers for Medicare and Medicaid Services and consult information from two PC organizations that were the sole PC consult providers in the study NHs.

Results: Four percent of all NH residents received a PC consult during the study period. Two-thirds had short NH stays, and 81% of short- and 27% of long-stay consult recipients were on the Medicare skilled nursing facility (SNF) benefit at the time of initial consult. Short- and long-stay NH residents with PC consults differed not only, in many respects, from NH residents generally but also from each other. Despite these differences, half of short-stay and 57% of long-stay residents were alive six months after initial consults. Residents dead at six months died at 33.5 and 34.5 median days (respectively) after initial consults. At six months, 65% of surviving short-stay consult recipients were in the community without hospice, while 59% of long-stay residents were in the NH without hospice or Medicare SNF care.

Conclusion: The high rates of SNF care and six-month survival among NH recipients of PC consults demonstrate the utility of these consults before Medicare hospice eligibility or use.

Keywords: Medicare; nursing homes; palliative care

Introduction

PALLIATIVE CARE (PC) consults in United States (U.S.) nursing homes (NHs) provide accessible PC expertise to residents with serious illness who may not yet qualify for or desire Medicare hospice. NH residents who receive PC consults have the potential to achieve the highest quality of life earlier in the trajectory of their serious illness.^{1,2} PC consults are similar to services received under the Medicare hospice benefit with two important distinctions—they do not require that an individual have a documented terminal prognosis of six months or less and they do not require the forfeiture of concurrent disease-modifying treatment such as that covered in the United States under Medicare's skilled

nursing facility (SNF) benefit.^{3,4} Consults have the potential, therefore, to reach many individuals with a serious illness who are not near the end of life.

Recent studies of PC in the NH setting focusing on decedent samples have demonstrated the benefits of NH PC consults before residents' deaths.^{3,5–7} Compared to propensity score-matched controls, one study found that those who received PC consults in the last 180 days of life had lower rates of hospitalization in the last 30 days of life, and those who received consults in the 61–180 days before death had lower rates of burdensome transitions near the end of life.⁵ Also, a NH-level panel study found NHs that introduced PC services between 2000 and 2010 had greater reductions in their hospitalizations in the last 30 days of life than facilities

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remaining without PC consults.⁶ In addition, a small single NH Veterans Affairs study of decedents found that receipt of PC services in a geriatric PC unit reduced the number of unnecessary end-of-life medications.⁸

These studies were limited, however, due to their focus on NH decedents. We know little about the characteristics of U.S. NH residents receiving PC services whose initial consults were six months before death. The purpose of this study is to describe the characteristics of NH residents who received PC consults in 54 NHs and compare them to NH residents generally. We also follow consult recipients for six months after their initial consult and describe their survival rates and sites of death, and for residents who survived six months after their initial consults, their care status. Our analyses are stratified by NH length of stay to distinguish between residents with longer NH stays (≥ 90 days) and those with shorter stays who almost always enter U.S. NHs after hospitalizations and often for rehabilitation or other skilled care.

Methods

This research used a longitudinal study design. We obtained a data use agreement from the Centers for Medicare and Medicaid Services (CMS) and the appropriate Health Insurance Portability and Accountability Act waiver approvals for CMS and the two hospice providers sharing PC consult data to release data to us. The study was approved by Brown University's Institutional Review Board.

Data

PC consult data from January 2008 through June 30, 2010 for patients in two counties in North Carolina and six in Rhode Island came from two hospice-affiliated PC providers. Because PC consultations are not billable under a specific Medicare payment stream, we needed provider data to identify residents with PC consults and consult timing. Ordered by a physician, PC consultations from both sites were provided by nurse practitioner PC specialists under the supervision of certified PC physicians. They followed typical procedures that include a review of diagnoses, prognoses, resident care preferences, and goals of care, and often include family meetings. A team of interdisciplinary PC specialists may visit a resident if warranted. The counties studied were chosen because the two providers were the exclusive providers of PC consults in these counties during the study period. Important data elements included person identifier, payment source, and date and location of first consult.

CMS provided Medicare enrollment, claims data, and NH resident assessment minimum data set (MDS) data for all NH residents in the study NHs. The enrollment file contains data on Medicare eligibility, Medicare Advantage enrollment, and dates of birth and death. Claims data, including hospital, SNF, emergency room, home healthcare, and hospice use, provide information on dates of services as well as diagnoses. The MDS data, mandated for all Medicare or Medicaid-certified NHs, include comprehensive demographic and clinical data on all NH residents upon admission and at least quarterly.

Sample

Using provider data, we identified 1181 individuals who received an initial PC consult in a NH setting between Jan-

uary 1, 2008 and June 30, 2010. Ninety-seven percent (1145) could be matched to Medicare enrollment data using the identifiers provided by the providers. We excluded 220 individuals who were not found to have an MDS assessment within 120 days before or 7 days after their PC consult, and 50 additional individuals who used Medicare Advantage in the 180 days before or after the consult date. It was necessary to exclude this latter group because Medicare claims are only available for Medicare fee-for-service individuals. Our final sample consisted of 875 NH residents with PC consults within 54 NHs.

To understand how consult recipients differed from the NH population generally, we identified a prevalence sample that consisted of all individuals who were present in the 54 NH facilities. To do this, we chose anyone who was present on the first Thursday in April in 2008, 2009, or 2010, who was not enrolled in Medicare Advantage for the 180 days before or after that date. The first Thursday in April was chosen to coincide with how researchers at Brown University define the prevalence population in their database Long-Term Care: Facts on Care in the U.S. (LTCFoCUS.org). This date minimizes the effects of seasonal and weekend fluctuations in admissions and discharges to give a better overall snapshot of a typical NH cohort. As members, themselves, of the overall NH population, residents in the PC cohort were eligible to be included if they were present on the chosen days, and individuals could be included more than once if they were present on the chosen day in more than one year.

Variables

We examined a number of characteristics often used to describe residents in NH studies. Short- and long-stay NH status were defined as fewer than 90 days or 90 or more days of continuous stay before the initial PC consult, allowing for hospitalizations of up to 10 consecutive days. Socio-demographic variables taken from the enrollment and MDS files included age, gender, marital status (married vs. other), and race (non-Hispanic White vs. other).

Other items taken from the MDS were functional impairment as measured by the activities of daily living (ADL) scale, ranging from 0 to 28 (higher values indicating greater impairment), and cognitive impairment measured by the Cognitive Performance Scale ranging from 0 to 6 categorized as intact to mild impairment (0–2), moderate to moderate severe (3–4), and severe to very severe (5–6). MDS items also included the frequency (none, less than daily, and daily) and intensity (mild, moderate, and severe) of pain in the 7 days before the assessment; weight loss (5% or more in the last 30 days or 10% or more in the last 180 days); stability of conditions (whether the resident's cognitive, ADL, and mood or behavior patterns were unstable), and whether or not the resident experienced an acute episode or flare-up of a recurrent or chronic problem.

We defined the presence of cancer, dementia, both, or none; chronic obstructive pulmonary disease (COPD); and congestive heart failure (CHF) using checkboxes in the baseline MDS, specific ICD-9 codes entered into the 'other diagnoses' fields of the MDS, as well as ICD-9 codes listed in the diagnosis fields of the claims files in the 12 months before the baseline date (i.e., the date of PC consult or the first Thursday in April). A list of the specific ICD-9 codes is

available upon request. Finally, indicators of do-not-resuscitate (DNR) orders, do-not-hospitalize (DNH) orders, and terminal prognosis (end-stage disease with an expected six or fewer months to live) were taken from the MDS, while the receipt of SNF care benefits at baseline came from examining dates of service on the SNF claims. Rates of missing information on individual items ranged from 0% to 1.9%.

Based on a comparison of the date of initial PC consult and resident date of death, we calculated the proportion of residents who were alive on each day up to six months post-

consult. We used the Medicare claims and NH assessment data to determine site of death or care status at six months for those who survived.

Analyses

Resident characteristics are presented for each of four groups: a short-stay prevalence sample, a short-stay PC sample, a long-stay prevalence sample, and a long-stay PC sample. Characteristics were compared across the two short-

TABLE 1. CHARACTERISTICS OF SHORT- AND LONG-STAY NURSING HOME RESIDENTS WITH PALLIATIVE CARE CONSULTS COMPARED TO SHORT- AND LONG-STAY PREVALENCE SAMPLES AND TO EACH OTHER

	Short NH stay (<i><90 days</i>)			Long NH Stays (<i>>=90 days</i>)			PC Short Stay vs. PC Long Stay ^a
	Prevalence sample (<i>n</i> =2500)	PC sample (<i>n</i> =570)	Sig	Prevalence sample (<i>n</i> =4977)	PC sample (<i>n</i> =305)	Sig	
Sociodemographic characteristics							
Age (mean, SD)	80.46 (12.30)	79.46 (11.62)		82.98 (11.42)	82.18 (10.61)		***
Male, <i>n</i> (%)	32.5	37.4	*	25.6	30.5		*
Married, <i>n</i> (%)	26.3	33.0	***	17.2	16.2		***
Non-Hispanic White, <i>n</i> (%)	95.3	95.3		93.3	91.5		*
Resident casemix, <i>n</i> (%)							
Cognitive Impairment (CPS Scale)			*				***
Intact to mild (0–2)	64.5	68.5		39.2	37.4		
Moderate to moderate severe (3–4)	30.9	25.4		47.6	50.2		
Severe to very severe (5–6)	4.7	6.2		13.2	12.5		
Diagnoses of Dementia and Cancer, <i>n</i> (%)			***				***
Cancer without dementia	12.4	22.0		5.1	6.2		
Cancer with dementia	7.3	9.8		9.9	11.5		
Dementia without cancer	38.3	32.8		58.6	61.0		
No cancer or dementia	41.9	35.4		26.4	21.3		
COPD	30.6	37.4	**	29.0	34.4	*	
CHF	37.9	43.7	**	34.5	38.7		
Weight loss	11.7	13.1		10.0	14.2	*	
ADL Score (mean, SD)	15.17 (6.38)	17.69 (6.15)	***	15.56 (7.94)	17.27 (7.05)	***	***
Pain, <i>n</i> (%)			***			***	***
No pain	46.1	30.2		69.4	51.2		
Pain less than daily	34.8	34.9		24.3	33.1		
Daily pain	19.2	34.9		6.4	15.7		
Pain intensity (among those with pain), <i>n</i> (%)			***			***	*
Mild	41.6	27.2		53.4	37.2		
Moderate	54.1	60.2		44.3	55.4		
Severe	4.3	12.6		2.3	7.4		
Stability of conditions, <i>n</i> (%)							
Patterns unstable	59.3	79.5	***	47.6	64.3	***	***
Acute episode/flare up	53.1	70.0	***	16.3	26.6	***	***
End-stage disease, six or fewer months to live	1.7	3.2	*	4.8	2.0	*	
Resident care planning, <i>n</i> (%)							
Do not resuscitate order	44.5	53.0	***	64.2	61.6		*
Do not hospitalize order	4.6	5.4		7.8	4.3	*	
On SNF care at baseline	56.3	81.1	***	13.1	26.9	***	***

^aThis column provides the significance levels for comparisons between the short NH stay PC sample ($n=570$) and the long NH stay PC sample ($n=305$).

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

CPS, Cognitive Performance Scale; Sig, significance level; NH, nursing home; PC, palliative care; COPD, chronic obstructive pulmonary disease; CHF, congestive heart failure; ADL, activities of daily living; SNF, skilled nursing facility.

stay groups, the two long-stay groups, and the two PC groups (i.e., short stayers and long stayers). We also examined survival rates of consult recipients six months after their initial consults and site of death for those who died within six months. For survivors, we examined locations of care at six months. All comparisons were tested using chi-square or two-tailed *t*-tests as appropriate in Stata 14.2.⁹

Results

Between January 1, 2008, and June 30, 2010, there were 27,118 unique residents served in the 54 NHs. Of those, 4.2% (1145) received an initial PC consult and a subset of 875 residents met our study criteria. The comparison group (i.e., the prevalence sample) included 7477 NH residents. Table 1 describes these groups, stratified by NH length of stay.

Short-stay NH residents

The short-stay PC sample differed significantly from short-stay residents generally (Table 1). Residents with PC consults compared to short-stay residents generally were more likely to be male and married, and to have cancer, COPD, and CHF. They were less likely to be cognitively and functionally impaired, but more likely to be in daily and intense pain. Nearly 80% of short-stay residents with consults were considered to have unstable conditions and 70% had recently experienced an acute episode or flare-up, compared to 59% and 53% (respectively) of NH residents generally. A terminal prognosis with an expected survival of six months or fewer was low for both groups, although higher for those with consults, and the rate of DNR orders was higher among those with consults compared to short-stay NH residents generally. Finally, 81% of residents with PC consults were on the Medicare SNF benefit at baseline, compared to 56% of short-stay residents generally.

Long-stay NH residents

There were fewer differences between long-stay residents with PC consults and long-stay residents generally (i.e., the long-stay prevalence sample). Those with consults were more likely than long-stay residents generally to have COPD, recent weight loss, and pain; also, they had more intense pain and were more functionally impaired. Nearly two-thirds (64%) of long-stay residents with consults had unstable conditions compared to 49% of long-stay residents generally, and 27% had acute flare-ups compared to 16% of residents generally. Last, long-stay residents with consults were less likely to have a documented terminal prognosis or a DNH order compared to long-stay residents generally and twice as likely to be on Medicare SNF at baseline (27% vs. 13%).

NH residents with PC consults

Not only did short- and long-stay PC recipients differ from their prevalent counterparts but they also differed from one another (Table 1). Short-stay consult recipients were younger and more often male, married, and non-Hispanic white than their long-stay counterparts. They had less severe cognitive impairment, less often had dementia diagnoses, and more often had cancer than did long-stay consult recipients. The rate of daily pain for short-stay consult recipients was more than double that for long-stay recipients (35% vs. 16%). Compared to long-stay consult recipients, pain for short-stay consult recipients was more severe when it did occur, and short-stay consult recipients were more likely those with long stays to have unstable patterns and acute episodes/flare-ups documented. Eighty-one percent of short-stay consult recipients were receiving Medicare SNF care at the time of their initial consult compared to 27% of long-stay recipients.

Figure 1 shows six-month survival curves after initial consult for short- and long-stay NH residents. Despite the differences in their casemix, those who died within 180 days of consult had similar median days of survival (after initial

FIG. 1. Six-month survival from the date of initial palliative care consult.

FIG. 2. Site of death for NH residents who received a palliative care consult by NH length of stay (those with six-month mortality). SNF, skilled nursing facility.

consult)—33.5 days for short stayers and 34.5 days for long stayers (respectively); and six-month survival rates did not differ significantly (at $p < 0.05$).

As can be seen in Figure 2, the sites of death for those dying within six months of PC consult varied widely for consult recipients with short versus long stays. Nearly 40% of short-stay consult recipients died outside the NH, while 60% of long-stay consult recipients died in the NH while on hospice.

Similar to decedents, the location and type of care at six months after initial PC consult varied widely. Just over 30% of short-stay consult recipients with six-month survival were in an NH at six months, and the majority were not receiving Medicare hospice or SNF care. Sixty-five percent were living in the community without Medicare home health or hospice care. Among long stayers, the majority (59%) were in the NH with neither Medicare hospice nor SNF care and only 22%

were in the community without Medicare home health or hospice (Fig. 3).

Discussion

Recent studies showing the benefits of PC consults in the U.S. NH setting have focused on decedents.^{3,5-7} To our knowledge, this is the first study to describe and longitudinally follow a cohort of NH residents after initial receipt of their PC consults. Four percent of residents present in the study NHs at any point during the study period received PC consults. Of these, nearly two-thirds were short-stay residents at the time of the initial consult. Notably, a full 80% of short-stay and 27% of long-stay consult recipients in our sample were on the Medicare SNF benefit at the time of their initial PC consult, and at least 50% of both groups survived six or more months after initial consult. For those who died, sites of death

FIG. 3. Among survivors, location of NH residents six months after having received an initial PC consult by NH length of stay.

differed by whether consult recipients had short or long NH stays, and for survivors, care status at six months after initial consult differed. These patterns within both groups remind us that PC consults are not just for those NH residents near death and should be accessible to a broad group of NH residents.¹⁰

Of interest, short- and long-stay consult recipients differed not only across several characteristics from short- and long-stay NH residents generally but also from each other. Among other things, short-stay consult recipients were more cognitively intact, but more likely to have cancer than their long-stay counterparts, and appeared to be in greater pain and in the midst of acute flare-ups of their conditions.

Consult recipients' high enrollment in Medicare SNF is an important finding suggesting that PC, as intended, reaches not only persons near the end of life but also those actively recovering from serious illness and/or not eligible for Medicare hospice. This is further supported by the high proportion of consult recipients alive at six months. The high need and use of PC consults for this group are further evidenced by a recent evaluation of the *Caring About Residents' Experiences and Symptoms (CARES) Program*, which is a model of PC consultation in the NH setting undertaken by Eastern Virginia Medical School (EVMS) and Sentara Lifecare.¹¹ In this single NH evaluation, researchers found that nearly 48% of residents recommended for initial PC consults were receiving SNF care, and 54% of participants requested curative treatment solely or in addition to suggested PC services, making them largely ineligible for hospice services.

We should not ignore, however, those residents who did die within six months of their initial consults. Despite the finding that fewer than 4% of either short or long stayers who received a PC consult had a documented terminal prognosis at the time of the initial PC consult (making 96% ineligible to receive Medicare hospice benefits), nearly 40% of both short and long stayers who died within six months died within the first three months after PC. This is evidence that PC services can fill an important gap even at the end of life, particularly when a six-month prognosis is not assessed (or documented). In 2009, in the United States, less than 50% of fee-for-service Medicare beneficiaries who died in an NH did so on the hospice benefit.¹²

Major strengths of this study are its longitudinal design and our ability to identify NH consults by obtaining data directly from PC providers. Also, we focused on the analyses in NHs where the PC providers were the sole PC providers during the study period; so we were able to capture all individuals who received PC consults in those facilities.

We are limited in generalizability because our study focused on only 54 NHs within Rhode Island and parts of North Carolina. Without a clear way to define palliative consults within the national Medicare files, however, broadening the scope of our findings will be difficult. We also exclude residents who used Medicare Advantage at any point in time six months before or after baseline because we do not have access to Medicare claims for these individuals. It is unclear how this elimination affected our findings.

This study is an important first step in describing the individuals in NHs who access PC consults and in understanding how consult recipients' characteristics and care trajectories differ by whether they are short- or long-stay NH residents. Information from this study can help to guide the development of guidelines for PC consult referral in NHs.

Further research can also increase our understanding of who might benefit most from a NH PC consult and consequently whether the low rate (4%) of NH PC consult receipt found in this study is appropriate.

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Author Disclosure Statement

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