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Brief Report

Cancer Care in the United States: Identifying End-of-Life Cohorts

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Abstract

Objectives: End-of-life care is increasingly recognized as an important part of cancer management for many patients. Current methods to measure end-of-life care are limited by difficulties in identifying cancer cohorts with administrative data. We examined several techniques of identifying end-of-life cancer cohorts with claims data that is population-based, geographically scalable, and amenable to routine updating.

Methods: Using Medicare claims for patients 65 years of age and older, four techniques for identifying end-of-life cancer cohorts were compared; one based on Part A data using a broad primary or narrow secondary diagnosis of cancer, two based on Part B data, and one combining the Part A and B methods. We tested the performance of each definition to ascertain an appropriate end-of-life cancer population.

Results: The combined Part A and B definition using a primary or secondary diagnosis of cancer within a window of 180 days prior to death appears to be the most accurate and inclusive in ascertaining an end-of-life cohort (78.7% attainment).

Conclusion: Combining inpatient and outpatient claims data, and identifying cases based upon a broad primary or a narrow secondary cancer definition is the most accurate and inclusive in ascertaining an end-of-life cohort.

Introduction

With a growing population over 65 years old,[1] accurate measurement of end-of-life medical services in patients with cancer is an important and understudied dimension of geriatric care. Although standardized end-of-life cohorts for Medicare beneficiaries have been defined and extensively studied,[2,3] there has been little effort to develop disease-specific cohorts, such as for cancer. One barrier to studies of end-of-life cancer care has the difficulty in assigning the cause of death to cancer for large populations.

Medicare data is one approach to measuring end-of-life cancer care with several advantages. Medicare claims files are readily available to researchers and include the population-based medical care experience of the elderly. Analyses can include the full range of utilization and are also amenable to routine updating over time.

The goal of this study was to develop a cohort of Medicare end-of-life patients using claims files. We developed several methods for identifying Medicare beneficiary decedents with a diagnosis of cancer and then evaluated them for cohort size and the likelihood that cancer was a major contributing cause of death.

Methods

Four cancer cohorts were based on fee-for-service Medicare beneficiaries Part A and B eligible age 65 years and older for the period 2001 to 2005. We first identified beneficiaries who died, and then searched within defined periods prior to death for utilization events indicating that the patient had cancer. Cohorts were then evaluated on the basis of the number of beneficiaries assigned to the cohort and the likelihood that patients receiving hospice care with a principal diagnosis of cancer were also found within the cohort.

Duplicate claims and claims with an allowable charge of $0 were excluded from the analyses. Patients were classified as black or non-black, based on the work of others advocating this dichotomization, and availability of racial data in the Medicare claims dataset.[2]

The first cohort included decedents whose last inpatient

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stay from the MedPAR file had a principal diagnosis of cancer (Part A Definition) (ICD-9 codes: 140-208 or 239.0-239.9, excluding V codes) or with a secondary diagnosis of cancer considered to be metastatic or with a poor prognosis, based on previous work by Iezzoni et al.[4] (see Appendix available online at www.liebertpub.com/jpm). By using a secondary diagnosis of cancer identified as severe, we were able to capture those subjects admitted to the hospital for a potentially associated condition (e.g., pneumonia), even though the secondarily listed cancer diagnosis was the likely cause of subsequent death.

In the next two cohorts, we used diagnoses on physician and other clinician claims indicate the presence of cancer. This method included patients with cancer without a recent hospital discharge related to their terminal illness but who received outpatient care. These cohort definitions used a 20% beneficiary sample Carrier File of Medicare Part B physician claims (Part B thereafter). These files contain dates of service and associated diagnosis codes for each physician claim for an individual enrolled in Medicare Part B.[5] The second cohort included patients who had claims with a primary diagnosis of cancer within the time frames specified above (Broad Definition). A diagnosis meeting these criteria had to occur two or more times, at least 6 days apart but not more than 120 days apart, with the later of the two claims occurring within the designated period from death. We then defined a third cohort using Part B data, but added a secondary diagnosis of a restricted set of severe cancers, similar to cohort 1 (Combined Definition).

Finally, we defined a fourth cohort based on the union of Part A and Part B claims from the sources above (Combined Part A Part B Definition). We selected a 20% beneficiary sample of the 100% Part A file comparable to the 20% Part B file. This sample was joined with the subjects in the Part B cohort that had a primary or secondary diagnosis of cancer using the methods outlined above.

We evaluated these cohorts four ways. First, we compared the number of deceased beneficiaries identified by each cohort with the U.S. vital records[6] estimates of the number of cancer deaths in those over 65 for the target year. Second, if the cohort members died of cancer, we would expect that a reasonable proportion of them would receive hospice services. We calculated rates of hospice utilization for the entire cohort using the Medicare Hospice File. Hospice enrollment was defined as the “admission” to hospice services, regardless of location, nearest to death.

Third, we assumed that the principal diagnosis in a hospice admissions was the likely cause of death[7] and then calculated the proportion of hospice patients with a cancer diagnosis that was also identified by our defined cohorts. Higher scores on this proportion indicate better “sensitivity” of a given cohort definition for detecting cases that died of cancer.

Finally, we calculated the proportions of true-positives within the cohorts. The denominator consisted of all members of a given cohort admitted to hospice, and the numerator the subset of those cases whose primary diagnosis for admission to hospice was cancer. Higher scores on this statistic indicated a given cohort definition identified a high proportion of true-positive cases in those receiving hospice care, and excluded cases that died of noncancer diagnoses.

Results

Based on a death year of 2005 and a 180-day predeath window, the Combined Part A Part B definition identified 58,978 patients representing 294,890 nationally when upweighted to 100% (Table 1). Adjusting this number for risk bearing HMO beneficiaries excluded from the analysis (6.1 million of 43 million total enrollees in 2005),[8] this cohort was 88.5% of the estimated number of deaths from cancer age older than 65 years in non-HMO patients according to 2005 U.S. vital records (333,337).[6]

The proportion of cohort members in 2005 receiving hospice benefits varied from 53% to 57% depending on the cohort definition. Hospice use increased monotonically from 2001–2005. These are rates are consistent with the upward trend of hospice care in cancer patients reported by McCarthy et al.[9]

Comparing the proportion of patients admitted to hospice with a primary diagnosis of cancer who were also found in the study cohorts assessed the sensitivity of the various cohort definitions to identify patients who died of cancer (Table 2). The Combined Part A Part B Cohort identified 80.1% of hospice patients with a primary diagnosis of cancer, suggesting this cohort definition is the most sensitive definition for identifying those who died of cancer. These results were consistent for all 5 years of data and for all three inclusion time windows.

Examining solely the cohort members who were admitted to hospice, Table 3 shows the proportion for which the principal hospice diagnosis was cancer. The Combined Part A cohort definition achieved slightly higher levels (around 95%) indicating the proportion of true positive to false positives is slightly higher in this cohort than the others.

Discussion

Varying definitions of cancer and place of service affect the number of patients identified for end of life cancer cohorts. Our analyses show that a cohort definition based on a union of Part A and Part B Medicare claims data, using a 180-day window prior to death, includes the largest number of patients while still overlapping with hospice patients with a principal diagnosis of cancer. The 180-day window corresponds to the 6-month eligibility criteria established by Medicare,[10] and is consistent with data showing that the majority of patients enroll in hospice in the 180 days prior to death.[9]

By taking advantage of national Medicare claims data as opposed to data sets limited to selected states or a health care system, we are more confident that our cohort definition is nationally representative of the elderly population. While no indicator of cause of death is perfect, our claims-based measure may have advantages over methods based on death certificates given research questioning the accuracy of vital statistics recording.[11–13] These studies suggest that cancer is often not listed as the underlying cause of death, leading to underestimation of cancer cases. By including the entire fee-for-service Medicare aged population, our cohort definition has the additional value of applicability to analyses at national, regional, state, county, or health service area levels.

There are a number of limitations in this approach. Medicare data cannot account for cancer patients who are under 65 years old and who are not disabled. Our definition

Table 1. End-of-Life Cancer Cohort Definitions and Proportion of Cohort Enrolled in Hospice Care, 2001–2005

Time		Part A			Part B[a]					Part A and B Combined Definition[a,c]		
						Broad Definition[b]		Combined Definition[c]				
Death year	Days before death[d]	Decedents with Part A claim within cohort period	# beneficiaries with cancer (1st or 2nd dx) (%)[c]	% Hospice	Decedents with Part B claim within cohort period	# with cancer	% Hospice	# with cancer	% Hospice	Decedents with Part A or B claim within cohort period	# beneficiaries with cancer (1st or 2nd dx)	% In hospice care
2005	365	1,138,521	162,982	54.6	1,427,170	275,655	55.6	283,925	55.4	1,428,245	327,110	55.1
	270	1,101,478	158,929	54.0	1,427,170	261,230	56.2	269,805	56.1	1,428,190	313,775	55.6
	180	1,050,794	152,362	52.7	1,427,170	240,690	56.7	249,780	56.5	1,428,145	294,890	56.0
2004	365	1,126,090	166,322	53.0	1,409,865	283,665	53.7	291,665	53.5	1,410,880	334,985	53.3
	270	1,089,608	162,215	52.3	1,409,865	266,190	54.5	274,565	54.3	1,410,810	318,970	54.0
	180	1,039,705	155,578	51.0	1,409,865	243,400	55.1	252,230	54.9	1,410,770	297,970	54.5
2003	365	1,153,414	169,701	51.0	1,455,805	299,725	50.5	307,295	50.5	1,457,000	348,265	50.3
	270	1,115,823	165,461	50.3	1,455,805	282,465	51.4	290,200	51.4	1,456,950	332,145	51.1
	180	1,065,143	158,647	49.0	1,455,805	257,325	52.0	266,530	52.0	1,456,920	309,770	51.6
2002	365	1,155,220	171,891	48.9	1,447,250	297,550	48.6	305,150	48.5	1,448,435	345,815	48.3
	270	1,118,319	167,611	48.2	1,447,250	280,165	49.5	288,135	49.4	1,448,380	329,820	49.0
	180	1,068,197	160,696	46.8	1,447,250	255,440	50.2	264,265	50.1	1,448,310	307,435	49.6
2001	365	1,126,610	170,549	47.4	1,417,630	286,665	47.1	293,995	47.0	1,419,075	335,035	46.7
	270	1,091,365	166,360	46.6	1,417,630	270,710	47.9	278,135	47.8	1,418,995	320,055	47.4
	180	1,042,751	159,569	45.3	1,417,639	247,815	48.7	255,845	48.5	1,418,915	299,080	48.0

[a] Twenty percent sample, up-weighted to 100%.
[b] ICD-9 definition: 140–208 or 239.0–239.9, excluding V codes.
[c] First diagnosis is ICD-9 codes 140–208 or 239.0–239.9, excluding V codes, or second diagnosis using Iezzoni definition, Appendix (available online at www.liebertpub.com/jpm).
[d] Maximum possible time span in days from death to admission date of last hospitalization.

Table 2. Of Those Patients in Hospice with a Primary Diagnosis of Cancer, Proportion of Patients Ascertained in Various Cohort Definitions with Diagnosis of Cancer

				Part B Definitions[a]		
Death year	*Days before death*[b]	*# of patients in hospice with cancer*	*Of those in hospice, % with Part A cancers cohort*[c]	*Of those in hospice, % within broad definition cohort*[d]	*Of those in hospice, % within combined definition cohort*[c]	*Of those in hospice, % within combined Part A and Part B definition cohort*[c]
2005	365	189,432	44.5	69.2	70.7	82.2
	270	186,555	43.6	67.9	69.5	81.3
	180	180,841	42.1	66.0	67.9	80.1
2004	365	185,480	45.2	70.3	71.7	83.2
	270	182,754	44.1	68.8	70.4	82.3
	180	176,961	42.6	66.7	68.5	80.9
2003	365	180,699	45.7	71.5	73.0	83.9
	270	178,049	44.6	70.1	71.6	82.9
	180	172,600	42.9	67.9	69.7	81.4
2002	365	175,455	45.8	71.1	72.4	83.2
	270	172,849	44.6	69.7	71.2	82.3
	180	167,500	42.9	67.4	69.1	80.6
2001	365	166,780	46.4	70.2	71.7	82.8
	270	164,387	45.2	68.9	70.5	81.8
	180	159,380	43.4	66.7	68.4	80.2

[a] Twenty percent sample, up-weighted to 100%.

[b] Maximum time span in days from death to admission date of last hospitalization.

[c] First diagnosis is ICD-9 codes 140–208 or 239.0–239.9, excluding V codes, or second diagnosis using Iezzoni definition, Appendix (available online at www.liebertpub.com/jpm).

[d] ICD-9 definition: 140–208 or 239.0–239.9, excluding V code.

Table 3. Of Cohort Members who Enter Hospice, Proportion That Have a Primary Hospice Diagnosis of Cancer

				Part B Definitions[b]				*Combined Part A or B Definition*[a,b]	
		Part A Definition[a]		*Broad Definition*[c]		*Combined Definition*[a]			
Death Year	*Days before death*[d]	*# beneficiaries*	*% with 1st hospice dx as cancer*	*# beneficiaries*	*% with 1st hospice dx as cancer*	*# beneficiaries*	*% with 1st hospice dx as cancer*	*# beneficiaries*	*% with 1st hospice dx as cancer*
2005	365	89,035	94.9	153,240	89.3	157,355	89.0	180,275	88.9
	270	85,776	94.8	146,930	90.5	151,295	90.2	174,600	89.9
	180	80,330	94.8	136,405	92.0	141,155	91.7	165,025	91.2
2004	365	88,114	95.2	152,265	89.0	156,080	88.8	178,455	88.8
	270	84,809	95.1	145,050	90.5	149,155	90.3	172,125	90.1
	180	79,409	95.1	134,180	92.2	138,560	92.0	162,245	91.6
2003	365	86,563	95.4	151,425	88.8	155,190	88.6	175,320	88.7
	270	83,214	95.4	145,130	90.1	149,025	89.9	169,710	89.9
	180	77,736	95.3	134,315	91.8	138,605	91.6	159,965	91.4
2002	365	84,104	95.7	144,710	90.0	147,980	89.9	166,925	89.8
	270	80,743	95.6	138,635	91.3	142,220	91.2	161,635	91.0
	180	75,269	95.6	128,260	92.8	132,355	92.6	152,460	92.3
2001	365	80,791	95.8	134,945	90.6	138,080	90.4	156,460	90.6
	270	77,581	95.8	129,775	91.7	132,995	91.5	151,720	91.5
	180	72,289	95.7	120,625	93.1	124,195	92.9	143,550	92.7

[a] First diagnosis is ICD-9 codes 140–208 or 239.0–239.9, excluding V codes, or second diagnosis using Iezzoni definition, Appendix (available online at www.liebertpub.com/jpm).

[b] Twenty percent sample, up-weighted to 100%.

[c] ICD-9 definition: 140–208 or 239.0–239.9, excluding V code.

[d] Maximum time span in days from death to admission date of last hospitalization.

relies on claims data, and not chart abstraction or other measures that might better indicate a diagnosis of cancer in the last months of life. It is possible that some patients were excluded from our cohort, particularly from the Part A definition, if a cancer diagnosis was listed lower than a primary or secondary diagnosis in the discharge records. This would negatively impact the sensitivity of our measure, but should do little to affect the specificity.

Using a cohort definition based on joined Medicare Part A and B data and a primary or secondary diagnosis of cancer, with a more severe secondary diagnosis, appears to yields the most appropriate nationally representative sample of cancer deaths for age older than 65. These cohorts will allow for analysis of trends and regional variation in cancer care near the end of life.

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Author Disclosure Statement

No competing financial interests exist.

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