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Medicare Beneficiaries With Advanced Lung Cancer Experience Diverse Patterns Of Care From Diagnosis To Death

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Abstract

Characterizations of average end-of-life care for people with cancer can obscure important differences in patients' experiences. Using Medicare claims data for 14,257 patients diagnosed with extensive-stage small-cell lung cancer in the period 1995–2009, we used latent class analysis to identify classes of people with different care patterns. We characterized care trajectories from diagnosis to death using time spent in five care settings—home, hospital inpatient unit (acute), hospital intensive care unit (ICU), postacute skilled nursing facility, and hospice—and transitions across these settings. We identified four classes of patients: 66 percent spent the time primarily at home, 11 percent were primarily in hospice, 17 percent were largely in an acute setting, and 6 percent were largely in an ICU. Patients in these classes differed significantly in terms of baseline clinical characteristics, survival length, time spent in hospice, site of death, and spending. The findings show substantial heterogeneity in patterns of care for patients with advanced cancer, which should be accounted for in efforts to improve end-of-life care.

Individual experiences of health care following a cancer diagnosis vary widely according to clinical needs and non-clinical factors such as practice patterns, accessibility and affordability of care, and patients' preferences.^{1–5} Yet little is known about the details of, and variation in, care patterns at the end of life for patients who have been diagnosed with advanced cancer.

The Medicare hospice benefit finances palliative care for beneficiaries with a survival prognosis of six months or less. Since the introduction of the benefit more than thirty years

ago, hospice use has increased dramatically—in 2014, 48 percent of Medicare decedents received hospice services, compared to 23 percent in 2000⁶— and in-hospital deaths have decreased.⁷ However, one-third of Medicare decedents receive less than a week of hospice. Hospice duration of at least one week is often used as a marker of high-quality care, and receiving fewer than three days of hospice is considered a marker of aggressive care and insufficient to provide the full benefits of hospice.^{7,8} For people with a serious cancer diagnosis, the Institute of Medicine⁹ and the National Comprehensive Cancer Network¹⁰ recommend that palliative care begin soon after diagnosis. Despite increasing emphasis on palliation, the use of aggressive care has also increased over time.^{7,11} This includes hospitalizations, emergency department visits, transitions across health care settings, and intensive care unit (ICU) admissions at the end of life.

Variation in end-of-life care has been examined previously using simple measures of disability or rates of transition across settings.^{12–14} One recent study stratified patients by survival length and then reported differences in service utilization.¹⁵ Another identified several spending trajectories in the last year of life but did not explicitly relate these to patterns of utilization.¹⁶ End-of-life spending has also been used to identify people with intensive end-of-life care who might benefit from palliative services.¹⁷

This study focused on Medicare beneficiaries diagnosed with extensive-stage small-cell lung cancer, an aggressive and chemosensitive cancer with a median survival time of eight to twelve months with treatment.¹⁸ Because of the short average survival length, end-of-life care begins at diagnosis for many people. Thus, this population afforded a unique opportunity to examine the complete course of health care use from diagnosis to death. We characterized care trajectories, defined as the periods of time spent in five distinct care settings, and the transitions across these settings. We then examined how groups of people with similar trajectories differed on baseline clinical characteristics, survival time following diagnosis, hospice duration, sites of death, and total spending.

Understanding variation in end-of-life care patterns may be useful in identifying subgroups of people who experience aggressive care and burdensome transitions, and it may shape efforts to improve care coordination, advance care planning, and palliative care provision in ways that account for the diverse experiences of people with advanced cancer.

Study Data And Methods

Study Population

We used data from the Surveillance, Epidemiology, and End Results (SEER) cancer registries and linked Medicare claims. We studied Medicare beneficiaries who were diagnosed with extensive-stage small-cell lung cancer in a SEER registry in the period 1995–2009 and followed them through death (if they died before January 2012). We required beneficiaries to have had two years of continuous enrollment in Medicare Parts A and B before their diagnosis (to measure prediagnosis characteristics), and we excluded people who were diagnosed at autopsy, had previous cancer diagnoses, received experimental therapy, or were enrolled in Medicare Advantage and those whose date of death was censored. There were 14,257 people in the final study population. (For sample

sizes at each stage of this inclusion and exclusion process, see online Appendix Exhibit A1.)¹⁹

Analyses

IDENTIFYING TRAJECTORIES OF HEALTH CARE USE—Using Medicare billing claims data, we classified each day from diagnosis to death into one of five mutually exclusive care settings: hospital inpatient unit (acute), hospital ICU, postacute care in a skilled nursing facility, hospice care (either at home or in a facility), or at home without receiving any Medicare-covered facility-based or hospice services (“home” could be in the community, a nursing home, or an assisted living facility).

We summarized care trajectories using two types of measures: number of days spent in each setting and number of episodes in each setting. Both types of measures were divided by survival time after diagnosis (in days), so that measures of the former were expressed as percentages of time spent in each setting, and measures of the latter were expressed as episode rates.

To identify people with similar trajectories, we applied latent class analysis.²⁰ This statistical method assumes an underlying structure of mutually exclusive categorical subgroups or classes. In our context, these subgroups were characterized by common patterns of end-of-life care. We used latent class analysis to group people who had similar values on ten summary measures of their health care trajectories, as defined above (that is, the percentages of time and episode rates for each of the five care settings). Appendix Exhibit A2 summarizes our grouping process.¹⁹

To determine the optimal number of latent classes, we implemented the analysis with one to seven classes and considered the following fit statistics: Akaike information criteria, Bayesian information criteria, Lo-Mendell-Rubin likelihood ratio test, and entropy. Furthermore, to focus the analysis on major patterns of care, in selecting a final model, we required that no class be smaller than 5 percent of the population. A model with four classes was determined to be optimal. In the Appendix, we provide fit statistics and summaries of models with different numbers of classes (Exhibits A3–A7) and the distribution of class membership probabilities for the four-class fit (Exhibit A8).¹⁹

CHARACTERIZING PEOPLE IN THE FOUR CLASSES—To further understand differences in individuals across classes, we implemented latent class regression to quantify the association of individual characteristics with class membership.

Using prediagnosis claims and registry information, we measured demographic characteristics (age, sex, race, marital status, and census region), significant comorbidities (dementia and score on the Charlson Comorbidity Index), disability (number of Medicare-provided functional aids), and socioeconomic indicators (months of enrollment in Medicaid in the two years before diagnosis and, in the ZIP code of residence, median household income, percentage of residents with no more than a high school education, and percentage of linguistically isolated residents ages sixty-five and older). A household is linguistically isolated if all members ages fourteen and older speak a language other than English and

none speaks English “very well.” Our measure was the percentage of senior residents in the patient’s ZIP code who lived in such households.

Using Medicare postdiagnosis claims data, we created two measures of chemotherapy treatment: whether a person received chemotherapy at any time after diagnosis, and the type of initial regimen received (that is, the first regimen initiated within six months of diagnosis), categorized as ambulatory with one of two major chemotherapy regimens (carboplatin plus etoposide or cisplatin plus etoposide) or any other chemotherapy. Furthermore, we examined survival time (days from diagnosis to death), care setting at the time of death, duration of hospice enrollment (none, less than one week, or one week or more), and total health care spending per day (on Medicare-covered services, excluding Part D drugs). Appendix Exhibit A12 provides additional details about these measures.¹⁹

We used multivariate latent class regression to examine the associations of latent class membership with the baseline clinical characteristics (demographic characteristics, comorbidities, disability, socioeconomic indicators, and initial chemotherapy regimen). Additionally, separate regressions estimated the associations of class membership with survival length, hospice duration, site of death, and total spending, respectively. To account for the uncertainty of latent class membership, we performed latent class regression using structural equation modeling. (Technical details about the latent class regression are provided in the “Step 4” section of the Appendix; the regression model coefficients and fitted means are in Appendix Exhibits A13 and 14.)¹⁹ To assess temporal trends, we examined how class prevalence changed across the study period. To characterize survival, we present class-specific Kaplan-Meier curves.

All latent class modeling was performed in Mplus, version 7.4. Additional analyses were performed in R, version 3.4.0.

Limitations

Several limitations of this study should be acknowledged. First, the study was limited to people with one form of aggressive cancer, so the trajectories we identified might not be generalizable to patients with other types of cancer. Furthermore, extensive-stage small-cell lung cancer is a particularly chemosensitive form of cancer, and treatment reduces symptoms and prolongs life for most patients.^{18,21}

Second, our measures of utilization relied on billing claims data, so we could identify only the patterns of utilization that appeared in fee-for-service Medicare claims. We did not identify services that were reimbursed by other payers (such as Medicaid), paid for directly by beneficiaries, or provided in an outpatient setting. Thus, episodes of care in the home setting might include residence in a nursing home or assisted living facility—services not covered by Medicare.

Third, our measures of the setting in which care was provided did not differentiate palliative care from curative care provided in an acute setting. Finally, our clinical measures came from cancer registry data instead of medical records, so they might not comprehensively characterize patients’ clinical status.

Study Results

Utilization and Survival in the Four Classes

The analysis revealed four classes of patients with substantially different patterns of care. The largest class (“home-dominated”) comprised people who spent most of their time at home without hospice (Exhibit 1). They had the longest survival time (Exhibit 2), so time spent in a hospital inpatient unit or ICU, and time receiving postacute care in a skilled nursing facility both constituted small percentages of total survival time, despite their spending more days in these settings than people in some other classes. About half of the patients in the home-dominated class enrolled in hospice care, with approximately one-third of these hospice recipients enrolling during the final week of life. Half of the people in the home-dominated class died in hospice, and a quarter died in the hospital. People in this class had the lowest mean daily spending. In this class, there was a bump in hospital care soon after diagnosis, followed by a second increase near the end of life (Exhibit 3). As expected, the proportion of people in this class who received hospice care rose quickly at the end of life.

The smaller hospice-dominated class was characterized by widespread hospice enrollment. Everyone in this class enrolled in hospice at some point (Exhibit 2), and on average they spent approximately half of their time receiving hospice care (Exhibit 1). Nearly everyone in this class died in hospice; only 1 percent died in an acute setting (Exhibit 2). Members of the class spent very little time in the ICU or a skilled nursing facility receiving postacute care (Exhibit 1). Only about a quarter of the members received chemotherapy. Members’ daily spending was similar to that of people in the home-dominated class. Hospitalization for members of the hospice-dominated class occurred soon after diagnosis, followed by a dramatic rise in hospice use, with nearly everyone enrolling within the first 75 percent of time between diagnosis and death. (Appendix Exhibit A10 shows the percentages of the entire study population in each health care setting over time, and Appendix Exhibit A11 shows the percentages for each class individually.)¹⁹

The acute-dominated class had a very short survival time (little more than a month) and spent a significant amount of time hospitalized in ordinary inpatient units and at home without hospice (Exhibit 1). Members of this class spent a greater percentage of time in acute care than members of the other classes did (Exhibit 1). Hospice utilization and ICU care were both low in this class. Approximately two-thirds of the class’s members did not receive any chemotherapy after diagnosis (Exhibit 2). They had the second-lowest rate of hospice use (not quite one-third), with approximately three-quarters of hospice recipients enrolling within a week of death. Overall, nearly half died in an acute setting, nearly one in five died in a postacute setting (skilled nursing facility), and almost one-third died in hospice. People in the acute-dominated class had the second-highest mean daily spending. The proportion of people in this class who were hospitalized increased steadily until two-thirds of the way through the course of their disease and then decreased (Exhibit 4). The proportion receiving postacute care followed a similar, but slightly lagged, pattern, and the proportion in hospice rose at the end of life.

The ICU-dominated class—the smallest of the four classes—was characterized by high ICU use and by spending equal amounts of time after diagnosis in the ICU and at home without hospice (Exhibit 1). The members of this class had the shortest mean survival time and lowest hospice use, with only one in five enrolling and having an average of one day of hospice care (Exhibits 1 and 2). They had the lowest rates of chemotherapy treatment (just below one-quarter). Nearly three-quarters of their deaths took place in an acute care setting, and they had the highest mean daily spending. The proportion of people in this class who were hospitalized steadily increased, with a small uptick in hospice care at the end of life (Appendix Exhibit A11).¹⁹

Class Differences in Baseline Characteristics

Overall, compared to people in other classes, members of the home-dominated class were the youngest and healthiest and had the most social or economic resources (Exhibit 5). Their average age at diagnosis was seventy-five years, half were male, and slightly more than half were married. They had the shortest period of Medicaid enrollment in the two years before diagnosis and the fewest mean Medicare-provided functional aids.

Compared to people in the home-dominated class (the reference group), members of the hospice-dominated class were less likely to be male. They had more Medicare-provided functional aids and were more likely to be diagnosed with dementia. They were more likely to live in the South and less likely to live in the Northeast.

Compared to members of the home-dominated class, people in the acute-dominated class were more likely to be single and had more impaired health, with a greater comorbidity burden and more use of required functional aids. They were more likely to live in the Northeast and less likely to live in the West. They lived in neighborhoods with lower median household incomes and greater linguistic isolation.

The ICU-dominated class had the longest enrollment in Medicaid and were generally sickest in the two years before diagnosis, as evidenced by their having the highest comorbidity burden and number of Medicare-paid functional aids. People in this class were more likely to live in the Northeast or South, compared to members of the home-dominated class.

Additionally, we examined the association between year of diagnosis and class membership to assess potential temporal trends. The probability of membership in the home- and acute-dominated classes declined across the study period, while the probability of membership in the hospice- and ICU-dominated classes increased (Appendix Exhibit A9 shows the proportion in each class by year of diagnosis).¹⁹

Discussion

These results emphasize the wide variation of care patterns from diagnosis to death for people with extensive-stage small-cell lung cancer, an aggressive cancer with a short survival length. While traditional aggregate descriptions mask variability across patients, we identified four distinct classes: The largest class (66 percent of the study population) spent most of the time between diagnosis and death at home, while 11 percent were primarily in

hospice, 17 percent spent a large proportion of time in a hospital inpatient unit, and 6 percent spent a significant amount of time in the ICU.

We observed notable differences across the classes in demographic and clinical characteristics. Members of the home-dominated class were healthiest at baseline, were most likely to receive chemotherapy, and had the greatest social support, as well as the longest survival time and lowest daily spending. The hospice-dominated class had lower baseline functional capacity than the home-dominated class, a low rate of chemotherapy, early hospice enrollment, and the second-lowest daily spending. The acute- and ICU-dominated classes, both characterized by significant hospitalizations, were constituted of individuals with more baseline comorbidities and longer baseline Medicaid enrollment than the two other classes. The extensive use of hospital-based care in the acute- and ICU-dominated classes was likely in response to greater acute need (because of greater severity of the extensive-stage small-cell lung cancer upon diagnosis or the presence of more comorbid conditions). Members of these classes had very short survival times and high spending.

In the small hospice-dominated class, everyone received hospice services, with the average hospice duration more than sixty days. This finding is consistent with a recent study of people with advanced cancer that found that longer survival time was associated with greater hospice use.¹⁵ Longer survival time may give patients greater opportunity to engage in care planning, which could make it more likely for them to receive care concordant with their preferences.

In contrast, nearly a quarter of the people in our study had care trajectories characterized by significant time in the hospital. Despite surviving approximately one month after diagnosis, members of the acute- and ICU-dominated classes averaged one or two hospitalizations, respectively, which suggests rapid and potentially burdensome transitions at the end of life. Because of their high use of acute care, these people had significantly higher mean daily spending than those in the other two classes. For both the acute- and ICU-dominated classes, rates of hospice enrollment were low (31 percent and 20 percent, respectively), and the most common site of death was the hospital (45 percent and 71 percent, respectively). These classes' particularly high rates of hospitalization and in-hospital deaths may reflect a greater need for acute care to manage their higher comorbidity burden and more severe symptoms. Thus, low rates of hospice care in these groups may reflect an unpredictable and rapid disease progression, in which the challenges of managing the acute presentation take precedence over hospice enrollment. It is also possible that some members of these classes might have chosen different care if they had had advance care planning discussions with their clinicians, as end-of-life discussions have been shown to reduce aggressive end-of-life care.^{22,23} During our study period, there were no Medicare reimbursement codes for advance care planning discussions with patients by physicians and other health care professionals. Such codes were added in 2016 and could help ensure that people receive care consistent with their preferences. However, people in these groups might have preferred aggressive care.

We also observed temporal trends in class membership: The numbers of people in the hospice- and ICU-dominated classes increased across the study period, while membership in

the acute- and home-dominated classes declined. This is consistent with national trends in increased use of both hospice and aggressive end-of-life care.^{7,11,24} Growth in the hospice-dominated class may be due to increased efforts to enroll individuals in hospice and changing preferences regarding end-of-life care. The decline in the acute-dominated class may be due to increased use of hospice services in acute facilities—which means that in-hospital deaths are increasingly being converted to hospice deaths, even if patients stay in acute facilities.

Current eligibility rules for the Medicare hospice benefit, which require patients to forgo further disease-directed care when enrolling in hospice, may contribute to the short hospice stays seen among many advanced cancer patients. This prohibition on concurrent care is particularly challenging in cancers characterized by highly chemosensitive tumors, such as extensive-stage small-cell lung cancer. Initiating chemotherapy, even in the final weeks of life, may be clinically appropriate for palliation in patients with a cancer that has such a short survival time.^{25–27} A policy allowing concurrent disease-directed and hospice care could result in more and earlier use of hospice services for these patients. In response to concerns about barriers to concurrent care, the Affordable Care Act authorized the Medicare Care Choices Model, a three-year demonstration project of concurrent disease-directed and hospice care. Some early evidence supports the effectiveness of hospice integration with oncology care, finding better quality of life, less use of aggressive care, and longer survival time.²⁸ Yet concerns have been raised that the eligibility criteria in this demonstration project create barriers to participation for many people.²⁹

Conclusion

Our findings demonstrate the wide variation in end-of-life care trajectories for Medicare beneficiaries diagnosed with extensive-stage small-cell lung cancer. This variability would have been obscured in summaries of average utilization. Clinical and policy efforts to improve the quality and value of care should take into account differences in individuals' care trajectories. For example, for members of the ICU-dominated class, efforts to minimize time spent in the ICU and burdensome transitions at the end of life must be balanced against patients' preferences for aggressive care and adequate symptom management, which might most appropriately be provided with concurrent disease-directed and palliative care in the hospital setting.

Given the notable heterogeneity among patients with this aggressive cancer, even greater variation in care trajectories might be expected among people with cancers that have higher cure rates or longer survival times. Additional disease-specific studies of heterogeneity in patient experiences are warranted, since understanding the spectrum of care trajectories—particularly those experienced by the sickest of the sick—is essential for developing effective policies to improve the quality of end-of-life care.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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NOTES

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EXHIBIT 3. Percentages of people diagnosed with extensive-stage small-cell lung cancer in 1995–2009 in the home-dominated class who were in each health care setting, by percentage of time from diagnosis to death

SOURCE Authors’ analysis of data for 1995–2009 from the Surveillance, Epidemiology, and End Results (SEER) cancer registries and linked Medicare claims.

NOTES People in the home-dominated class spent most of their time from diagnosis to death at home without hospice. “Hospital” refers to ordinary inpatient units and intensive care units.

EXHIBIT 4. Percentages of people diagnosed with extensive-stage small-cell lung cancer in 1995–2009 in the acute-dominated class who were in each health care setting, by percentage of time from diagnosis to death

SOURCE Authors’ analysis of data for 1995–2009 from the Surveillance, Epidemiology, and End Results (SEER) cancer registries and linked Medicare claims.

NOTES People in the acute-dominated class spent a large portion of their time from diagnosis to death in a hospital inpatient unit. “Hospital” refers to ordinary inpatient units and intensive care units.

EXHIBIT 1
Health care trajectory summaries for four classes of patients diagnosed with extensive-stage small-cell lung cancer in 1995–2009

Class											
Home-dominated (<i>n</i> = 9,458)				Hospice-dominated (<i>n</i> = 1,502)				Acute-dominated (<i>n</i> = 2,397)			
Care setting	Time	Mean days	Mean episodes	Time	Mean days	Mean episodes	Time	Mean days	Mean episodes	Time	Mean episodes
Home	85%	247	5.3	35%	44	5.8	38%	14	0.9	40%	1.6
Acute	7	21	4.3	9	12	6.5	43	16	0.6	15	1.8
ICU	2	5	1.1	2	2	1.2	3	1	0.1	40	1.6
Postacute	2	6	0.4	2	3	1.4	12	5	0.1	3	0.1
Hospice	4	13	1.4	54	69	1.4	4	2	0.8	2	0.2

SOURCE Authors' analysis of data for 1995–2009 from the Surveillance, Epidemiology, and End Results (SEER) cancer registries and linked Medicare claims.

NOTES Of the four classes (defined in the text), home-dominated accounted for 66 percent of the sample, hospice-dominated for 11 percent, acute-dominated for 17 percent, and intensive care unit (ICU)-dominated for 6 percent. Care trajectories comprise a sequence of care episodes, each of which is a set of consecutive days in the same care setting. "Time" is from diagnosis to death.

EXHIBIT 2
Health care utilization measures for four classes of patients diagnosed with extensivestage small-cell lung cancer in 1995–2009

Class	ICU-dominated			
	Home-dominated	Hospice-dominated	Acute-dominated	ICU-dominated
Mean survival (days)	292	129	38	30
Chemotherapy	78%	26%	36%	24%
Place of death				
Home	16	5	8	5
Hospice	51	94	29	20
Hospital	27	1	45	71
Postacute	6	0	19	4
Length of time in hospice				
None	46	0	69	80
1 week or less	20	1	23	16
More than 1 week	35	99	8	4
Mean daily spending	\$646	\$665	\$1,026	\$1,740

SOURCE Authors' analysis of data for 1995–2009 from the Surveillance, Epidemiology, and End Results (SEER) cancer registries and linked Medicare claims.

NOTES The classes are defined in the text. Survival is time from diagnosis to death. Details on the latent class regression models are shown in Appendix Exhibit A14 (see Note¹⁹ in text).

EXHIBIT 5

Selected characteristics of the study sample

	Class			
	Home-dominated (ref)	Hospice-dominated	Acute-dominated	ICU-dominated
DEMOGRAPHIC CHARACTERISTICS				
Race/ethnicity				
White (ref)	89%	91%	88%	86%
Black	6	6 ****	7	9
Hispanic	1	1	1	2
Other	4	2 ****	4	4
Mean age at diagnosis (years)	75	77 ****	77 ****	76
Male	50%	40% ****	49%	48%
Marital status				
Married (ref)	52	40	42	46
Single	6	7	9 **	10
Separated or divorced	9	10	10	12
Widowed	29	39	34	31
Missing	3	4	5	2
Census region				
Midwest (ref)	21	21	22	15
Northeast	18	13 ****	22 **	20 ****
South	25	32 **	24	24 **
West	37	34	32 ****	41
SOCIOECONOMIC CHARACTERISTICS				
Mean months of Medicaid enrollment in 2 years before diagnosis	3.1	4.5 ****	4.6 ****	5.4 ****
Linguistically isolated people ages 65 and older in ZIP code	17%	17%	19% **	19%
People ages 25 and older in ZIP code with no more than a high school education	29%	30%	29%	28%
Median household income in ZIP code	\$47,350	\$44,800	\$46,330 **	\$47,150
CLINICAL CHARACTERISTICS IN THE 2 YEARS BEFORE DIAGNOSIS				
Mean Charlson comorbidity score	2.2	2.5	2.7 ****	3.0 ****
Mean Medicare-provided functional aids	0.3	0.4 **	0.4 ****	0.5 ****
Diagnosis of dementia	5%	11% **	8%	9%
Type of initial chemotherapy				
Ambulatory cisplatin plus etoposide	8%	2% ****	1% ****	<2% ****
Ambulatory carboplatin plus etoposide	27	7 ****	3 ****	3 ****
Other	42	18 ****	33 ****	21 ****
None (ref)	24	72	63	76

SOURCE Authors' analysis of data for 1995–2009 from the Surveillance, Epidemiology, and End Results (SEER) cancer registries and linked Medicare claims.

NOTES The classes are defined in the text. The results are from a multivariable latent class regression model that includes all of the characteristics in the table as predictors. Linguistically isolated people are defined in the text. “ZIP code” refers to the patient’s ZIP code of residence. “Initial chemotherapy” refers to the first regimen received in the six months following diagnosis. Significance denotes difference from the home-dominated class.

**
p < 0:05

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p < 0:001

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