5-23-2018

Impact of diffuse large B-cell lymphoma on visits to different provider specialties among elderly Medicare beneficiaries: challenges for care coordination

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TBM

ORIGINAL RESEARCH

Impact of diffuse large B-cell lymphoma on visits to different provider specialties among elderly Medicare beneficiaries: challenges for care coordination

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Cite this as: *TBM* 2018;8:386–399
doi: 10.1093/tbm/ibx071

Abstract

Newly diagnosed diffuse large B-cell lymphoma (DLBCL) can pose significant challenges to care coordination. We utilized a social-ecological model to understand the impact of DLBCL diagnosis on visits to primary care providers (PCPs) and specialists, a key component of care coordination, over a 3-year period of cancer diagnosis and treatment. We used hurdle models and multivariable logistic regression with the Surveillance Epidemiology and End Result-Medicare linked dataset to analyze visits to PCPs and specialists by DLBCL patients (n = 5,455) compared with noncancer patients (n = 14,770). DLBCL patients were more likely to visit PCPs (adjusted odds ratio, AOR [95% confidence interval, CI]: 1.25 [1.18, 1.31]) and had greater number of visits to PCPs (β, *SE*: 0.384, −0.014) than noncancer patients. Further, DLBCL patients were more likely to have any visit to cardiologists (AOR [95% CI]: 1.40 [1.32, 1.47]), endocrinologists (1.43, [1.21, 1.70]), and pulmonologists (1.51 [1.36, 1.67]) than noncancer patients. Among DLBCL patients, the number of PCP visits markedly increased during the treatment period compared with the baseline period (β, *SE*: 0.491, −0.028) and then decreased to baseline levels (−0.464, −0.022). Visits to PCPs and specialists were much more frequent for DLBCL patients than noncancer patients, which drastically increased during the DLBCL treatment period for chronic care. More chronic conditions, treatment side effects, and frequent testing may have increased visits to PCPs and specialists. Interventions to improve care coordination may need to target the DLBCL treatment period, when patients are most vulnerable to poor care coordination.

Keywords

Non-Hodgkin's lymphoma, Care coordination, Physician visits, Specialist visits, Chronic care

Implications

Practice: Primary and chronic care of DLBCL patients should not be neglected during the cancer treatment and follow-up periods as DLBCL patients may have higher chronic care needs than noncancer patients. Furthermore, DLBCL patients at risk for mental illness should be referred to suitable mental health specialists when necessary.

Policy: Policymakers who want to improve care coordination for cancer patients may need to target the cancer treatment period.

Research: Future studies need to investigate the cancer patients' perceived barriers to care coordination among their primary care providers, oncologists, and specialists.

INTRODUCTION

Non-Hodgkin's lymphoma (NHL) is the most prevalent blood cancer with approximately 72,580 new cases of NHL expected to be diagnosed in 2016 [1]. Diffuse large B-cell lymphoma (DLBCL) is the most common subtype of NHL (30%–58%) and commonly occurs in adults above 64 years of age [2]. Approximately 27,650 new cases of DLBCL were diagnosed in the USA in 2016, with a higher rate in males (8.4 per 100,000 individuals) compared with females (5.6 per 100,000 individuals) [3]. The survival rates for DLBCL were highest for White females and lowest for Black males (2 years: 63%–68%, 5 years: 55%–62%, and 10 years: 48%–55%) [3]. DLBCL can lead to secondary cancers [4], posttraumatic stress [5], and poor quality of life in patients diagnosed with DLBCL [6]. Furthermore, 82.0% of older adults have pre-existing chronic physical or mental health conditions [7, 8]. Therefore, individuals diagnosed with DLBCL receive care from multiple providers such as the oncologists, primary care physicians (PCPs), and other medical specialists (e.g., cardiologist, endocrinologists, psychologists, and others). Although not specific to DLBCL, older adults visit an average of six different providers in a year [9]. Previous studies have found that under the fee-for-service system, the receipt of uncoordinated care from multiple providers can lead to medication errors [10], duplication of services [11], emergency room visits [12], unplanned hospital readmissions [13], increased costs [11, 14], preventable hospitalizations [14] and ultimately worsening patient health [15]. In its report on cancer survivorship, the National Academy of Medicine (formerly called the Institute of Medicine)

recommended that individualized survivorship care plans should be developed to increase care coordination for cancer patients. The U.S. Department of Health and Human Services [16] and the National Quality Forum [17] have also developed strategic frameworks of care to identify novel models of care and include effective care coordination as one of the care quality measures.

Care coordination may be further compromised with newly diagnosed cancer [11] because cancer patients need care from multiple providers for their chronic conditions and cancer. For example, among breast cancer patients, visits to oncologists and PCPs increased after breast cancer diagnosis [18–20]. Colorectal cancer patients had more visits to PCPs after the treatment period compared with the prediagnosis period [21, 22]. These findings suggest that cancer patients may be receiving care from both oncologists and PCPs. However, DLBCL patients may consult their PCPs or other medical specialists for symptoms before being referred to an oncologist because they may experience vague symptoms such as painless swelling of lymph nodes, fever, and weight loss [23]. The visits to PCPs and other medical specialists may continue during and after the cancer treatment period because, unlike other cancers, DLBCL can affect multiple organs [24]. In a cross-sectional survey conducted among NHL patients, 87.1% visited PCPs or other medical specialists, in addition to their oncologists [25]. However, the investigators did not examine provider visits by patients with DLBCL which is markedly different in treatment and survival prognosis from other subtypes of NHL [2]. DLBCL is an aggressive form of NHL and is often treated with intense therapeutic regimens such as stem cell transplant [26, 27]. It is possible that an aggressive treatment of DLBCL can either increase or decrease the visits to PCPs and other medical specialists. For example, DLBCL treatment can worsen other chronic conditions, or patients may have new diagnoses of chronic conditions, leading to an increase in PCP visits. However, it is also possible that due to prioritization of cancer care, DLBCL patients may not continue to see their PCPs or other medical specialists, specifically during the cancer treatment period [28]. This study will clarify the impact of an aggressive cancer such as DLBCL on change in primary and specialist visits and the associated care coordination challenges among them. To the best of our knowledge, no study has investigated whether DLBCL affects visits to PCPs and other medical specialists, an indicator of care coordination. It is important to examine DLBCL patients' visits to PCPs because cancer follow-up care in primary care settings is cost-effective [29]. While oncologists are responsible for the treatment of cancer, they may be less effective than PCPs and other medical specialists in providing care for other chronic conditions [30].

Theoretical framework

DLBCL patients' visits to different providers can be influenced by patients' personal characteristics as well as external social and healthcare environmental factors. These multiple levels of influence on an individual's health behavior can be best understood by using the social-ecological model (SEM) of health behavior [31]. The SEM is an ecological model, which seeks to incorporate the multilevel factors that influence health behavior and the interaction of these factors. Including concepts at the macro level, such as the community, and at the micro level, such as individual biology or psychology, the SEM is capable of incorporating a diversity of models at the individual, organizational, and environmental levels to better understand whether an individual will engage in a behavior. This model is well suited to the context of care coordination, as factors such as the patient's disease state and the larger healthcare system play a role in the treatment that a patient receives.

We utilized the SEM to examine factors associated with visits to PCPs and other medical specialists [31], including (a) intrapersonal factors: patient's socio-demographic characteristics, chronic conditions, and cancer treatments received; (b) healthcare system factors: density of physicians and facilities; and (c) community factors: region, urbanacity, area poverty, area education, and formal and informal social support systems [32–34]. We used a nationally representative linked dataset of cancer registries and Medicare claims in the USA. The primary objective of this study was to evaluate the impact of newly diagnosed DLBCL on visits to PCPs and other medical specialists among the elderly Medicare beneficiaries compared with those without any cancer. The secondary objective was to examine the change in PCP visits and use of medical specialists before and after DLBCL diagnosis.

METHODS

Study design

We utilized a retrospective longitudinal design with 12-month preindex and 24-month postindex periods. Because provider visits may increase among older adults with DLBCL for noncancer reasons such as an increase in age and chronic conditions, we included a comparison group of noncancer patients to examine the impact of DLBCL on change in provider visits over time. This is a stronger study design than those currently in the literature.

For the DLBCL patients, pre- and postindex periods were identified using the DLBCL diagnosis date as the index date. For the noncancer patients, pre- and postindex periods were derived using randomly selected dates of service from inpatient or outpatient Medicare claims. The DLBCL treatment period lasts for approximately 6 months [2]. Hence, the pre- and postindex periods were divided into six equal time intervals of 6 months each. For DLBCL patients, the

preindex period included baseline (T1) and prediagnosis (T2) and postindex period comprised treatment (T3), posttreatment (T4), short follow-up (T5), and long follow-up (T6) periods.

Data sources

We used data from following sources: (a) Surveillance Epidemiology and End Results (SEER)–Medicare database; (b) 5% Medicare sample for patients without any cancer; and (c) Area Health Resource File (AHRF). The SEER is a comprehensive database of 20 population-based tumor registries in the USA that collects information for all the newly diagnosed cancer cases such as demographics, cancer site, date of cancer diagnosis, and cancer pathology (e.g., stage and grade) [35]. The SEER mortality data are provided by the National Center for Health Statistics, and the epidemiological data on cancer rates are derived periodically from the Census Bureau [35]. The SEER-Medicare linked data include cancer patients, who are also enrolled in Medicare. Medicare is the primary health insurer for a majority of adults aged 65 years and older in the USA [36]. About 93% of patients in SEER with age 65 years and above are matched with their Medicare enrollment files by the National Cancer Institute and the Centers for Medicare and Medicaid Services [37]. The Medicare claims of cancer patients can be used to derive detailed information on medical treatment, chronic conditions, healthcare utilization, and expenditures. We used Medicare data from the following files: Medicare Provider Analysis and Review (MEDPAR–inpatient data), Outpatient Standard Analytical Files (SAF–outpatient data), carrier claims (physician claims data), Home Health Agency (HHA–home health services), and durable medical equipment (DME–medical equipment use) to measure provider visits, chronic conditions, and DLBCL treatments in this study [36]. The noncancer cohort was derived from a random 5% sample of Medicare beneficiaries residing in the SEER areas. Individuals in the 5% sample who are also present in the SEER cancer cohort are removed to obtain a random sample of noncancer cases [35, 37].

The AHRF is a publicly available data file provided by the Department of Health and Human Services which contains information on more than 6,000 variables for each of the U.S. counties [38]. The AHRF contains data on the availability of health professionals, healthcare facilities, and socioeconomic and environmental characteristics of each county. We used the state and county Federal Information Processing Standard (FIPS) codes to link the AHRF files with the SEER-Medicare dataset to measure the county-level healthcare system and community factors.

Study population

The DLBCL was identified using the International Classification of Diseases for Oncology–Third Revision (ICD-O-3)/World Health Organization 2008 codes: 13, 14, 15, 16) during 2003–2011. The noncancer patients were derived from a random 5% sample of Medicare beneficiaries who resided in SEER areas between 2003 and 2011 and were not diagnosed with any cancer, except basal cell carcinoma. We selected a 10% random sample of noncancer patients to keep the ratio of DLBCL to noncancer patients at 1:3, which is considered optimal for high statistical power [39].

The following exclusion criteria were applied to both DLBCL population and noncancer sample: (a) missing values for any demographic factor (e.g., age, sex, race/ethnicity, and region), (b) not alive during the observation period, (c) less than 66 years of age, (d) having end-stage renal disease (ESRD), (e) enrolled in managed care plans, (f) not continuously enrolled in Medicare parts A and B during the pre- and postindex periods, and (g) not having any PCP visit during the entire observation period (Figs. 1 and 2). Additional inclusion criteria were applied to the DLBCL population: We included individuals if they had only one primary cancer (except basal cell carcinoma) and if their cancer was not diagnosed from autopsy or death certificate.

Measures

Dependent variables

The dependent variables for our study included any visit to PCPs and other medical specialist. Further, we analyzed the number of PCP visits among those with at least one PCP visit. The provider visits were measured every 180 days (i.e., T1 through T6) and were derived from the National Claims History (NCH) files. The PCP specialties included general practice, family practice, internal medicine, geriatric medicine, nurse practitioner, or physician assistant [40]. Visits to other medical specialists included (a) cardiologists among patients with any heart condition; (b) endocrinologists among patients with diabetes; (c) mental health specialists (psychologist or psychiatrist) among patients with depression and/or anxiety; (d) pulmonologists among patients with asthma or chronic obstructive pulmonary disease (COPD); and (e) rheumatologists among patients with arthritis. We identified the specialty of a physician by using the Health Care Financing Administration (HCFA) specialty codes. The HCFA specialty codes from the SEER-Medicare dataset have been used in previous studies to examine the role of physician specialty in the care of breast and colorectal cancer patients [40–42].

Cancer status independent variable

The key independent variable was the presence of DLBCL versus no cancer, which belonged to the domain of intrapersonal factors as per SEM.

SEM independent variables

The independent variables in our study included both time-varying and time invariant variables. The

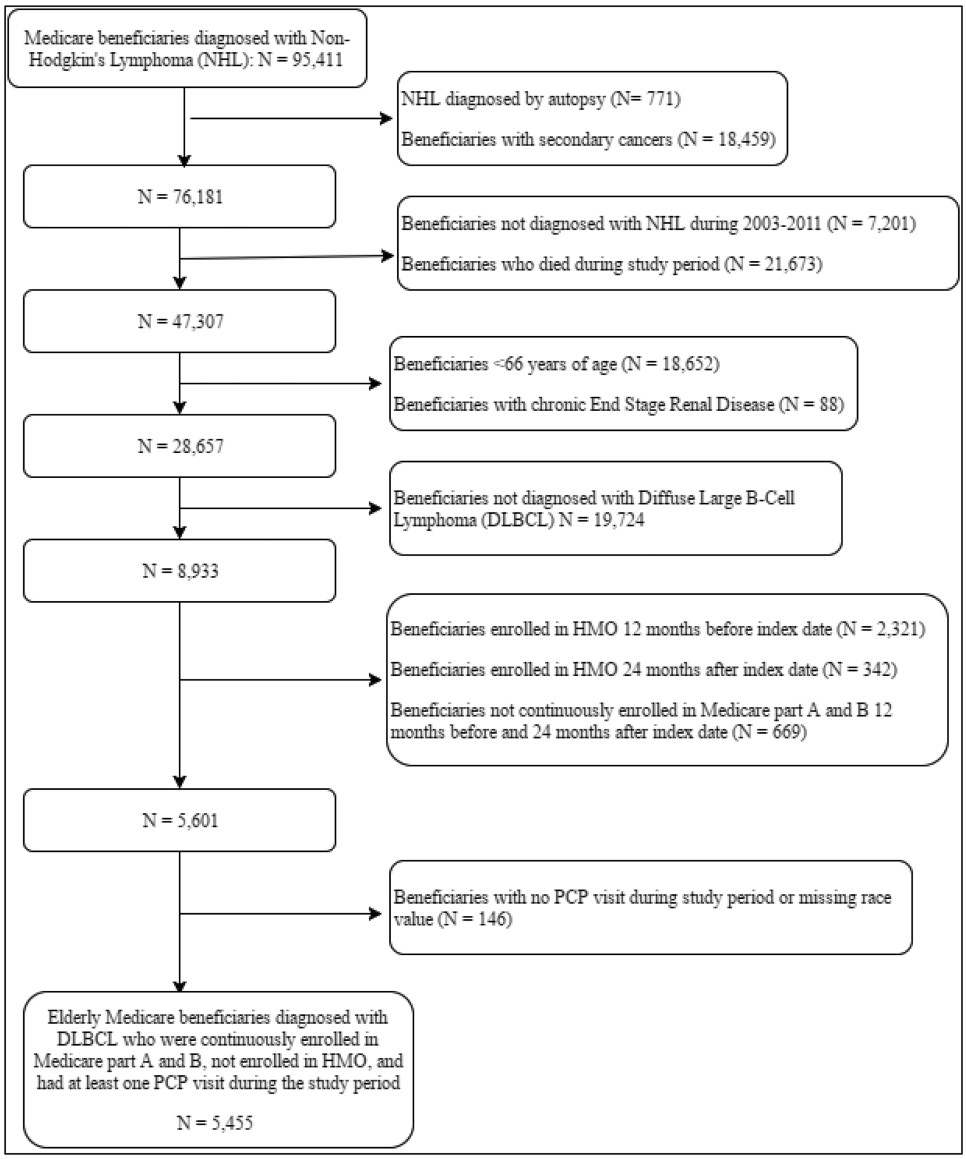

Fig. 1 | Flowchart of sample selection for elderly Medicare beneficiaries with diffuse large B-cell lymphoma.

time-varying factors included chronic conditions (arthritis, diabetes, any heart condition, mental condition, and respiratory condition) and DLBCL treatments (chemotherapy, radiotherapy, immunotherapy, and stem cell transplant). The time-varying factors were measured repeatedly during each time interval from T1 to T6. All other intrapersonal, healthcare system and community factors were time invariant and were measured during 1 year before the index date. All intrapersonal factors were measured at the individual level from the SEER-Medicare dataset. The healthcare system and community factors were measured at the county level from the AHRF dataset.

Intrapersonal factors

These factors included (a) age at index date (66–69, 70–74, 75–79, or ≥80 years); (b) sex (male or female); and (c) race/ethnicity (non-Hispanic White, non-Hispanic African American, Hispanic, or others). Our study examined the impact of DLBCL on visits to specialists in patients with specific chronic conditions. Hence, we measured individual chronic conditions, instead of a comorbidity index. We used specific International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) diagnosis codes to measure each of the following chronic conditions during any visit to PCP or specialist: (a) arthritis (osteoarthritis or rheumatoid arthritis); (b) diabetes; (c) any heart condition (cardiac arrhythmia, coronary artery disease, or congestive heart failure); (d) any mental condition (depression or anxiety); (e) any respiratory condition (asthma or COPD); and (f) DLBCL stage from the Ann Arbor staging system (Stage I, II, III, or IV). We used the Healthcare Common Procedure Coding System (HCPCS) codes, revenue center codes, and ICD-9-CM procedure codes from Medicare inpatient, outpatient, and physician

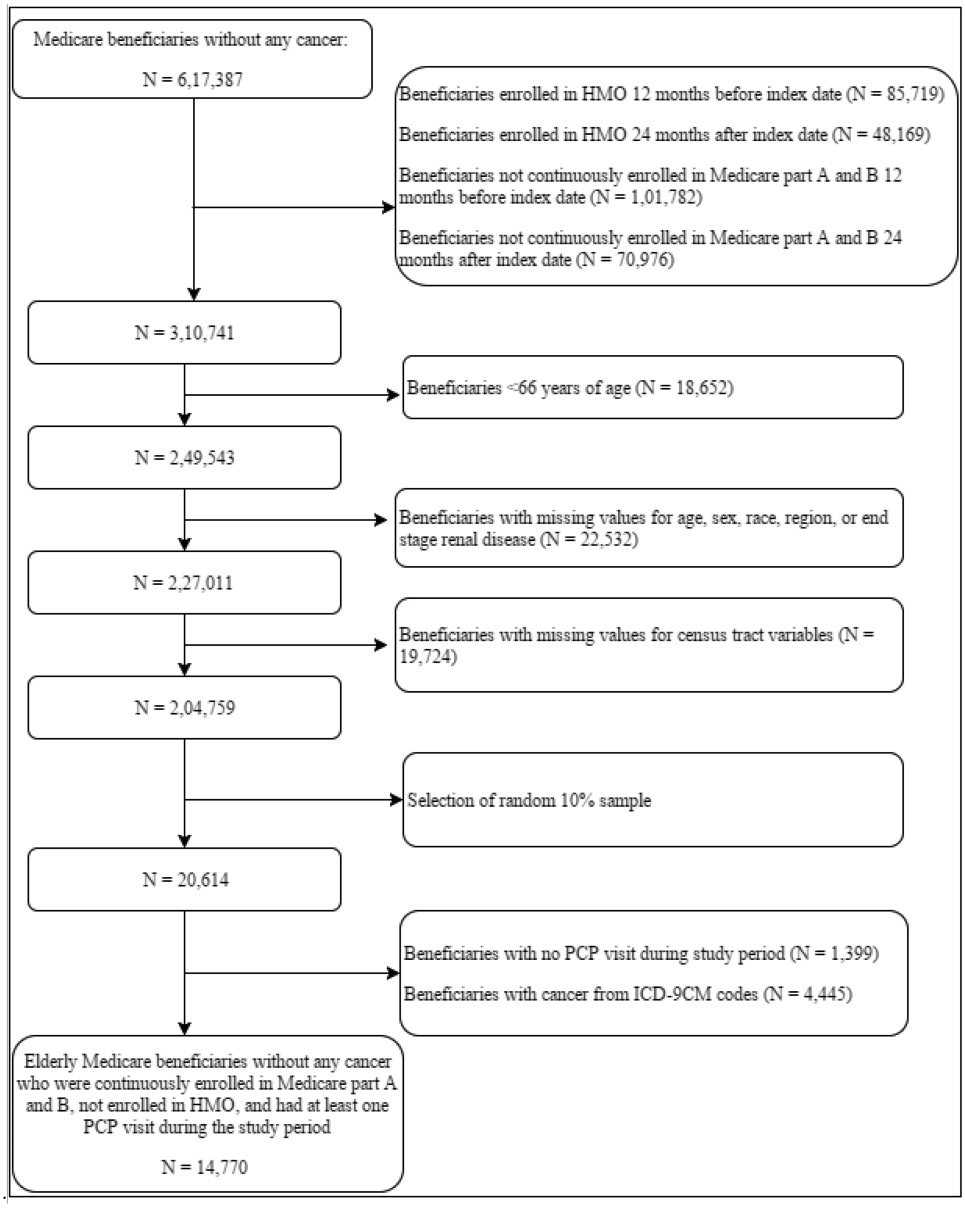

Fig. 2 | Flowchart of sample selection for elderly Medicare beneficiaries with no cancer.

claims files to measure the treatments of (a) chemotherapy; (b) radiotherapy; (c) immunotherapy; and (d) stem cell transplant.

Healthcare system factors

Healthcare system factors were measured at the county level. These factors included (a) health professional shortage area for PCPs (whole county, part of county, or no shortage); (b) quartiles of average number of hospitals per 10,000 older adults above 65 years of age (0.56, 0.97, 1.31, and 3.46); and (c) quartiles of average number of Federal Qualified Health Centers (FQHC) per 10,000 older adults above 65 years of age (0.01, 0.37, 0.94, and 3.68).

Community factors

Community factors included (a) geographic region (North-East, South, North-Central, or West); (b) rurality: We used urban/rural recode to classify region into metro (counties with <250,000 to 1 million population), urban (counties with 2,500 to >20,000 population), and rural (counties with <2,500 population); (c) percentage of Blacks; (d) percentage of Hispanics; (e) social or cultural cohesion measured by percentage of non-English-speaking individuals above 18 years of age; (f) county percentage of individuals between 18 and 64 years of age without health insurance (quartiles: 13.10, 17.70, 22.57, and 28.72); (g) county average travel times to work (quartiles: 19.73, 24.19, 27.44, and 30.95);

and (h) county percentage of individuals with below high-school education (quartiles: 8.44, 12.27, 16.31, and 25.01). In addition to the variables guided by SEM, we also included time and index year as covariates in all the models.

Statistical analysis

We used chi-square tests to analyze the model-driven unadjusted differences in intrapersonal, healthcare system and community factors between DLBCL and the noncancer patients. Due to multiple levels of data at county and patient level, the observations might be correlated. Further, as repeated observations were made for PCP visits from T1 to T6, each subject was clustered over time as well. To account for the nonindependence of observations, we used the population-averaged logistic regression models (also known as generalized estimating equations—GEE) with unstructured correlation structure to analyze the relationship between DLBCL and visit to providers [43]. GEE provide a robust approach to the analysis of longitudinal and hierarchically clustered data. The main advantage of GEE is in the unbiased estimation of population-averaged regression coefficients that are robust to any misspecification of the correlation structure [43].

For change in PCP visits, we used GEE with the hurdle models to analyze any visit to PCPs and the number of PCP visits. A hurdle model analyzes the two processes of generating zeroes and positive values separately [44]. The first part of the model, known as "hurdle at zero," analyzes the occurrence of an outcome (i.e., PCP visit or no visit). The second part of the model, known as "above the hurdle," analyzes the positive values of the outcome (i.e., number of PCP visits above zero) [41]. GEE with logistic regression was used for the first part, and GEE with negative binomial regression was used for second part of the hurdle model. We conducted regression models with stepwise addition of patient-level and county-level factors to analyze PCP visits. We first entered patients' cancer status (DLBCL vs. no cancer) followed by the individual-level factors and then the county-level factors to understand the association of factors at different hierarchical levels.

Our preliminary analysis indicated that there were significant differences in characteristics between the DLBCL and noncancer patients. To reduce this observed selection bias between the DLBCL and noncancer patients, we derived inverse probability treatment weights (IPTW, also known as propensity scores) by conducting a logistic regression on DLBCL versus no cancer with the following independent variables: sex, race/ethnicity, age, index year, and chronic conditions. These IPTWs were used as weights in all the unadjusted and adjusted analyses [45, 46]. IPTW technique gives weights to case and control cohorts to create a pseudo-population in which the case assignment (DLBCL or noncancer) and covariates are independent of each other. IPTW weighting technique is considered superior to propensity score matching, which may often substantially reduce sample size. Hence, study's conclusions will only apply to the selected subset of patients that could be matched [47]. All analyses were conducted using STATA version 14 [48].

RESULTS

DLBCL patient characteristics

In this study, a majority of DLBCL patients were white (87.9%) and resided in metro areas (83.0%). A higher proportion of DLBCL patients were females (55.5%), lived in West region (43.2%), and were ≥75 years of age (55.2%). There were some differences in baseline demographic characteristics between DLBCL and noncancer patients. Before adjusting with IPTW, DLBCL patients had a higher percentage of males, Whites, and those above 75 years of age, compared with noncancer patients (see Appendix 1).

Hurdle model: impact of DLBCL on any visit to PCP and number of PCP visits

A higher proportion of DLBCL patients visited PCPs compared with noncancer patients, which increased during the DLBCL treatment period (Table 1). Figure 3 displays the differences in any visit to a PCP between DLBCL patients and those without cancer from T1 to T6. Figure 4 summarizes the differences in the predicted number of PCP visits between the DLBCL and noncancer patients. Without any adjustments for chronic conditions, the average number of visits to a PCP were higher among those with DLBCL compared with the noncancer patients (T1: 3.57 vs. 3.46; T2: 4.29 vs. 3.44; T3: 8.36 vs. 3.55; T4: 5.12 vs. 3.61; T5: 4.41 vs. 3.63; T6: 4.50 vs. 3.82). After adjusting for the presence of chronic conditions at each time period, DLBCL patients still had a higher predicted number of PCP visits compared with noncancer patients (T1: 5.00 vs. 3.27; T2: 4.86 vs. 3.42; T3: 5.28 vs. 3.45; T4: 4.99 vs. 3.53; T5: 4.73 vs. 3.53; T6: 4.48 vs. 3.54).

From the unadjusted Model 1, DLBCL patients were more likely to visit PCPs (AOR = 1.39, 95% CI = [1.32, 1.46]) and had more PCP visits (β = 0.428, *SE* = −0.015) than noncancer patients. The regression coefficients for PCP visits remained the same after adjusting for the demographic characteristics in Model 2. However, the addition of chronic conditions as covariates in Model 3 considerably reduced the regression coefficients for any PCP visit (AOR [95% CI] = 1.24 [1.18, 1.31]) and number of PCP visits (β [*SE*] = 0.382 [−0.015]), indicating their importance in accounting for PCP visits. After adjusting for all the SEM covariates in Model 4, the coefficients remained identical to those found in Model 3.

Table 1 | Description of Any Visit to Different Provider Specialties During T1–T6 Among Elderly Medicare Beneficiaries with Diffuse Large B-Cell Lymphoma (DLBCL) and Noncancer Patients

	T1	T2	T3	T4	T5	T6
			DLBCL patients (%)			
Primary care physician	75.3	84.1	92.3	81.4	80.5	81.0
Cardiologist	70.2	62.8	83.7	50.7	46.0	46.6
Endocrinologist	7.6	7.0	8.8	6.6	6.0	6.1
Mental health specialist	34.9	30.6	31.7	36.7	32.2	37.1
Pulmonologist	25.8	23.7	34.1	18.5	15.2	14.0
Rheumatologist	18.1	14.3	8.7	7.4	7.1	6.7
			Noncancer patients (%)			
Primary care physician	75.1	75.5	82.2	75.7	77.3	77.9
Cardiologist	64.5	54.9	51.9	46.4	45.3	44.6
Endocrinologist	6.1	5.3	5.1	4.7	4.5	4.8
Mental health specialist	31.1	33.9	30.6	33.9	35.6	32.6
Pulmonologist	22.6	17.7	15.2	13.3	12.8	12.1
Rheumatologist	11.0	7.9	7.5	6.3	6.1	5.6

Surveillance Epidemiology and End Results Program (SEER)-Medicare 2003–2011. Percentages represent patients with any visit to the physician during T1–T6. Any visit to other medical specialist was analyzed only among patients with the corresponding chronic condition (e.g., any visit to endocrinologists was analyzed among those with diabetes). T1: baseline; T2: prediagnosis; T3: treatment; T4: posttreatment; T5: short follow-up; T6: long follow-up.

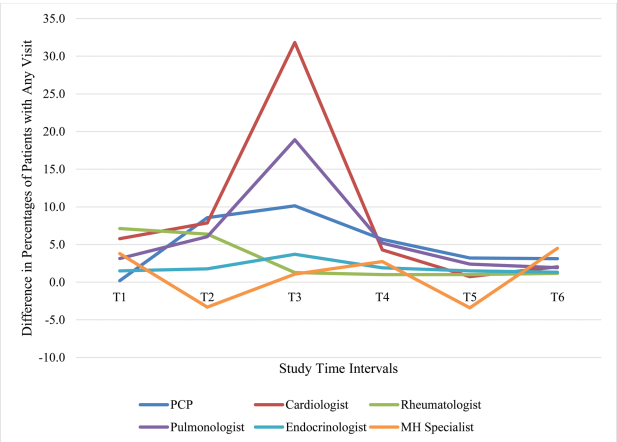

Fig. 3 | Differences in any visit to primary care physician and other medical specialists between elderly Medicare beneficiaries with DLBCL and no cancer. SEER-Medicare 2003–2011. Based on the differences in percentages of patients with any visit to provider between DLBCL and noncancer patients. T1: baseline; T2: prediagnosis; T3: treatment; T4: posttreatment; T5: short follow-up; T6: long follow-up. *DLBCL* diffuse large B-cell lymphoma.

SEM independent variables and any visit to PCP and number of PCP visits

The following SEM variables were associated with higher odds of any PCP visit (AOR [95% CI]) and higher number of PCP visits (β [*SE*]): Females compared with males (AOR [95% CI] = 1.38 [1.32, 1.45]; β [*SE*] = 0.067 [−0.010]), patients with age ≥80 compared with those aged 66–69 years (AOR [95% CI] = 1.31 [1.23, 1.39]; β [*SE*] = 0.145 [−0.013]), other racial minorities compared with non-Hispanic Whites (AOR [95% CI] = 1.24 [1.13, 1.36]; β [*SE*] = 0.077 [−0.021]), those living in South compared with North-East (AOR [95% CI]=1.55 [1.42, 1.70]; β [*SE*] = 0.072 [−0.018]), and those having arthritis (AOR [95% CI] = 1.57 [1.50, 1.64]; β [*SE*] = 0.190 [−0.009]), heart disease (AOR [95% CI] = 1.51 [1.45, 1.57]; β [*SE*] = 0.333 [−0.010]), respiratory conditions (AOR [95% CI] = 1.46 [1.39, 1.54]; β [*SE*] = 0.227 [−0.011]), mental health conditions (AOR [95% CI] = 2.23 [2.08, 2.40]; β [*SE*] = 0.333 [−0.013]), or diabetes (AOR [95% CI] = 1.82 [1.74, 1.91]; β [*SE*] = 0.202 [−0.010]) compared with those without arthritis, heart disease, respiratory conditions, mental health conditions, or diabetes, respectively. Those living in counties with more hospitals (AOR [95% CI] = 0.90 [0.83, 0.98]; β [*SE*] = −0.039 [−0.017]) and higher average travel times (AOR [95% CI] = 0.83 [0.76, 0.89]; β [*SE*] = −0.061 [−0.016]) were less likely to have any PCP visit and had fewer PCP visits compared with counties with less hospitals and lower average travel times, respectively.

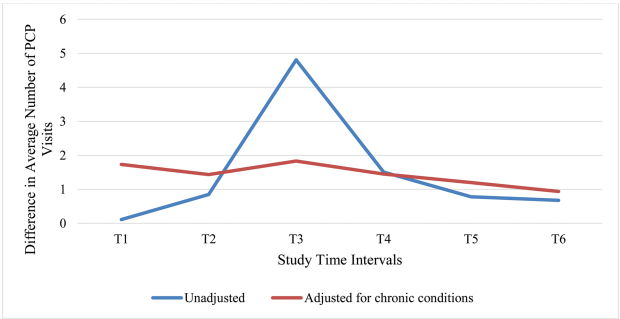

Fig. 4 | Unadjusted and adjusted differences in average number of visits to primary care physicians between elderly Medicare beneficiaries with diffuse large B-cell lymphoma and no cancer. SEER-Medicare 2003–2011. Calculated among those with at least one primary care physician visit. T1: baseline; T2: prediagnosis; T3: treatment; T4: posttreatment; T5: short follow-up; T6: long follow-up.

Table 2 | Unadjusted and Adjusted Estimates from Negative Binomial Regressions with Generalized Estimating Equation on Number of Visits to Primary Care Physicians (PCPs) Among Elderly with Diffuse Large B-Cell Lymphoma (DLBCL) Using Inverse Probability Treatment Weights

	Model 1			Model 2		
	β	*SE*	*p*	β	*SE*	*p*
Time						
Baseline, T1	Ref.			Ref.		
Prediagnosis, T2	0.201	−0.017	<.0001	0.134	−0.016	<.0001
Treatment, T3	0.872	−0.020	<.0001	0.491	−0.028	<.0001
Posttreatment, T4	0.337	−0.020	<.0001	0.027	−0.022	.209
Short follow-up, T5	0.188	−0.020	<.0001	−0.121	−0.020	<.0001
Long follow-up, T6	0.220	−0.020	<.0001	−0.108	−0.022	<.0001

Surveillance Epidemiology and End Results Program (SEER)-Medicare 2003–2011. Model 1: unadjusted; Model 2: adjusted for age, sex, race, region, rural/urban, marital status, arthritis, diabetes, any heart condition, depression/anxiety, asthma/chronic obstructive pulmonary disease, DLBCL stage, radiotherapy, chemotherapy, immunotherapy, stem cell transplant, county% black, county% hospitals, county% without health insurance, and county% below high-school education.

SE standard errors.

Impact of DLBCL on any visit to other medical specialists

Figure 3 displays the differences in any visit to other medical specialists between DLBCL patients and those without cancer from T1 to T6. From unadjusted analyses, a higher percentage of DLBCL patients visited cardiologists, endocrinologists, pulmonologists, and rheumatologists compared with noncancer patients (Table 1). However, with regard to mental health specialists, we did not observe a clear pattern of use among DLBCL patients. After adjusting for all the SEM covariates, DLBCL patients were more likely to visit cardiologists (AOR [95% CI] = 1.40 [1.32, 1.47]), endocrinologists (1.43 [1.21, 1.70]), and pulmonologists (1.50 [1.36, 1.67]) than patients with no cancer.

SEM-independent variables and any visit to other medical specialties

Those with arthritis (AOR [95% CI] = 1.09 [1.04, 1.14]), asthma (1.18 [1.13, 1.24]), mental health conditions (1.39 [1.31, 1.47]), or diabetes (1.17 [1.12, 1.23]) were more likely to have any visit to cardiologists compared with those without arthritis, asthma, mental health conditions, or diabetes, respectively. Older adults with heart conditions (1.31 [1.14, 1.50]) or mental health conditions (1.23 [1.08, 1.40]) were more likely to have any visit to endocrinologists compared with those without heart conditions or mental health conditions, respectively. Older adults with any heart condition (1.62 [1.45, 1.81]), mental health conditions (1.31 [1.19, 1.44]), or diabetes (1.11 [1.01, 1.22]) were more likely to have any visit to pulmonologists than those without any heart condition, mental health conditions (depression or anxiety), or diabetes, respectively. Also, females compared with males (0.75 [0.71, 0.79]), African Americans compared with Whites (0.76 [0.69, 0.85]), those living in the North-Central (0.83 [0.74, 0.92]) or West (0.78 [0.71, 0.85]) region compared with North-East, and those living in rural areas (0.80 [0.73, 0.89]) compared with metro areas were less likely to have any visit to cardiologists.

Change in number of PCP visits over time in DLBCL patients

The results from the negative binomial regressions for change in PCP visits among DLBCL patients are displayed in Table 2. From unadjusted analysis in Model 1, the number of PCP visits increased from baseline (T1) to prediagnosis (T2), treatment (T3), posttreatment (T4), and follow-up periods (T5 and T6). However, after adjusting for SEM covariates in Model 2, we observed that the number of PCP visits increased from baseline (T1) to prediagnosis (T2)

and treatment (T3) periods and decreased during the follow-up periods (T5 and T6).

SEM-independent variables and number of PCP visits in DLBCL patients

Factors associated with a higher number of visits to PCPs among DLBCL patients included age ≥80 years compared with 66–69 years (β [*SE*] =0.082 [0.025]), females compared with males (0.059 [0.017]), and those living in the South (0.089 [0.032]), North-Central (0.139 [0.033]), or West (0.100 [0.027]) region compared with North-East. Presence of chronic conditions was the strongest predictor of having a higher number of PCP visits among DLBCL patients. DLBCL patients with arthritis had 48% higher, diabetes had 62% higher, any heart condition had 97% higher, depression or anxiety had 111% higher, and asthma or COPD had 48% higher number of PCP visits during 6 months compared with DLBCL patients without arthritis, diabetes, any heart condition, depression or anxiety, and asthma or COPD, respectively (see Appendix 2).

With respect to DLBCL treatments, those receiving radiotherapy (0.085 [0.023]) or immunotherapy (0.099 [0.028]) had a higher number of PCP visits compared with those not receiving radiotherapy or immunotherapy, respectively. Those receiving stem cell transplants (−0.060 [0.017]) had a lower number of PCP visits than those not receiving stem cell transplant. With respect to community factors, those living in counties with a lower number of health-insured individuals (−0.074 [0.033]) and higher number of Blacks (-0.093 [0.032]) had a lower number of PCP visits than those living in counties with a higher number of health-insured individuals and a higher number of Blacks. Also, older adults living in counties with a lower education level (0.118 [0.031]) had a higher number of PCP visits than those living in counties with a higher education level.

DISCUSSION

In this first study of its kind, we examined the impact of newly diagnosed DLBCL on visits to different provider specialties to understand the challenges for care coordination. We analyzed the impact of DLBCL on any PCP visit, the number of PCP visits, and any visit to other medical specialists by using a robust study design that compared DLBCL patients with cancer-free patients. Our study findings indicated that DLBCL patients were more likely to visit PCPs and had higher number of PCP visits compared with those without any cancer, even after adjusting for intrapersonal, healthcare system, and community factors. These findings are consistent with a previous study in breast cancer patients who had higher PCP visits than noncancer patients [18].

We found that DLBCL patients were more likely to visit other medical specialists compared with noncancer patients. This is a unique finding because none of the published studies examined the relationship between cancer diagnosis and visits to other medical specialists, a key indicator of the need for care coordination. This finding suggests problems for care coordination for patients enrolled in fee-for-service Medicare because Medicare does not compensate the providers for communicating with other providers for care coordination. Providers have to face many challenges even with the availability of electronic health records due to a lack of interoperability between electronic health information systems [49].

With respect to change in PCP visits, our study findings are somewhat consistent with previous studies in colorectal and breast cancer patients, who were found to increase in their visits to PCP during the posttreatment period (i.e., 1 year after cancer diagnosis) [18–21]. Our study results indicated that the PCP visits increased threefold during the treatment period. One possible explanation for more visits to PCPs and other medical specialists among DLBCL patients is the presence of multiple chronic conditions. We observed that DLBCL patients had higher prevalence of diabetes, arthritis, any heart condition, depression or anxiety, and asthma or COPD than noncancer patients. Our findings also indicated that many patients were newly diagnosed with chronic conditions after DLBCL diagnosis and treatment, which statistically explained the increase in the number of PCP visits over time. Further, patients' pre-existing chronic conditions may have worsened due to DLBCL treatment. These results suggest that acute medical care for newly diagnosed conditions and increased care for pre-existing conditions may have escalated visits to PCPs.

The presence of multiple chronic conditions may also explain the higher visits to specialists among patients with unrelated comorbidity, such as higher visits to endocrinologists by mental health patients. Also, the chemotherapy and stem cell transplant are associated with significant side effects such as cardiotoxicity [50] and loss of bone density [51]. These side effects may be another reason for the increase in visits to specialists during the treatment period. This sharp increase in provider visits poses significant challenges to care coordination. DLBCL patients may face greater difficulties in care coordination because the roles of PCPs and other medical specialists have not been properly defined during the cancer treatment period [52, 53]. It is often unclear who should be responsible for such problems as cardiotoxicity or other vague symptoms during the treatment phase, which could be side effects of treatment, exacerbation of chronic conditions, or acute illness.

Surprisingly, we did not find a significant difference in visits to mental health providers among older adults diagnosed with both DLBCL and mental health conditions compared with those without any cancer, after adjusting for time, index year, and

other SEM factors. As the diagnosis and treatment of DLBCL lead to significant long-term psychiatric morbidity such as anxiety, depression, posttraumatic stress disorder, and lower health status [54–56], it is concerning that DLBCL patients' visits to mental health providers did not change. PCPs and oncologists may need to refer older adults with DLBCL diagnosed with mental health conditions to suitable mental health providers when necessary.

Further research is required on the reasons for the low number of visits to mental health specialists by DLBCL patients with mental health conditions. Such studies and future policy efforts may help in increasing DLBCL patients' visits to mental health specialists, when necessary. It is also important for the PCPs, other medical specialists, and oncologists to communicate about the DLBCL patients' ongoing treatments and health status with each other. Future studies are needed to examine whether DLBCL patients face difficulties in communication among their providers because of a sudden increase in visits during the DLBCL treatment period. New modes of interprofessional communication could result in improved health outcomes.

Another critical area for research is the interventions to improve care coordination for cancer patients. It is important to investigate whether the strategic frameworks developed by the U.S. Department of Health and Human Services [16] and the National Quality Forum [17] can be implemented in the context of cancer care and can improve care coordination for older adults with cancer and multiple chronic conditions. Another measure for improving the care coordination between oncologists and PCPs is the use of survivorship care plans. In response to the National Academy of Medicine's (formerly Institute of Medicine) report on cancer survivorship, many groups have developed specific care plans for cancer patients [57, 58]. Another effective method is to provide reimbursement for improving care coordination. For example, Medicare recently added a fee code that reimburses physicians for providing care coordination services. Recent studies have shown that a shared electronic medical record (EMR) system such as in the Veterans Administration health system can be helpful for improving the communication between PCP, other specialists, and oncologists [59]. Interventions to increase direct communication through fax, telephone, or e-mail, rather than relying on the patient may also be successful in improving care coordination. The effectiveness of these interventions in improving care coordination can be measured through patient or provider satisfaction surveys [60]. Transfer of information such as patient's medical history, treatment, or lab results from one physician to other can also be measured to assess good care coordination [60].

Our study findings should be interpreted in the context of some limitations. We used the HCFA provider specialty codes given in the Physician/Supplier Claims file (NCH) of the SEER-Medicare dataset to identify the provider specialties in this study. Although the HCFA codes have been used in previous studies on older adults with cancer [40, 61, 62], these codes may not capture all the visits to different provider specialties [63]. For example, DLBCL patients may have received mental health care from social workers or other behavioral practitioners. These specialties are not included in the HCFA codes, and hence, we could not measure them in this study. The purpose of our study was to examine the burden and opportunities for care coordination during the different phases of care among older adults with DLBCL. We did not investigate the actual provider–provider interaction or patients' and providers' experiences of care coordination in this study. Only the first diagnosis of DLBCL was analyzed in our study as the index date. We did not include a recurrence or relapse of DLBCL as it may not be identified reliably. Our study results can be generalized to Medicare fee-for-service beneficiaries who resided in SEER regions only. Another limitation of our study results is time-dependent confounding by DLBCL treatment [64]. Although DLBCL treatments and chronic conditions were repeatedly measured in this study, possible change in treatment side effects over time may have affected provider visits. Lastly, we estimated the population-averaged impact of some SEM factors on provider visits. Hence, our study results with these factors (e.g., county-wide educational level) should not be used to design care coordination interventions to target individual patients' risk characteristics.

The strengths of our study include the use of SEER-Medicare database with nationally representative data to examine the care of older adults with newly diagnosed cancer. We examined the visits to other medical specialists over a 3-year time period spanning the cancer diagnosis, treatment, and follow-up periods that had not been analyzed before. We used a comprehensive SEM framework to examine the association of various personal and contextual factors with the visits to different provider specialties among older adults with DLBCL. Further, we utilized a robust study design with a noncancer comparison group and time-varying diagnosis of chronic conditions in our study.

CONCLUSIONS

The elderly Medicare beneficiaries with DLBCL were more likely to visit PCPs or other medical specialists and had higher number of visits to PCPs compared with noncancer patients. The side effects of aggressive DLBCL treatment and more frequent contact with healthcare system may have led to increased diagnosis of other chronic conditions, which partially explained the higher visits to PCPs

and specialists. The time period immediately after DLBCL diagnosis needs to be targeted to implement interventions to improve care coordination between the oncologist, PCP, and other medical specialists.

Acknowledgements: The study findings have not been reported before and the manuscript has not been submitted elsewhere. The authors have full control of all the primary data and they agree to allow the journal to review the data if requested. No funding was received for this study.

Author contributions: All authors made substantial contributions to the conception and planning of this manuscript, analysis and interpretation of the data, drafting and critical revision, and approval of the final submitted version of the manuscript.

Conflict of Interest: The authors declare that they have no conflict of interest.

Primary Data: The authors have full control of all the primary data and they agree to allow the journal to review the data if requested.

Ethical Approval: The study was approved by the West Virginia University Institutional Review Board.

Compliance with Ethical Standards

Informed Consent: Not applicable. De-identified health insurance claims data of Medicare beneficiaries was used in this study.

Appendix 1 | Description of Selected Characteristics of Elderly Medicare Beneficiaries with Diffuse Large B-Cell Lymphoma (DLBCL) and Noncancer Patients Before and After Inverse Probability Treatment Weights

	DLBCL		Noncancer			DLBCL	Noncancer
	N	%	*N*	%		Col. wt %	Col. wt %
All	**5,455**	**27.0**	**14,770**	**73.0**	**Sig.**	**27.0**	**73.0**
Age (years)					<.001		
66–69	1,071	19.6	4,452	30.1		27.3	27.3
70–74	1,374	25.2	3,914	26.5		26.4	26.2
75–79	1,373	25.2	2,786	18.9		20.6	20.6
≥80	1,637	30.0	3,618	24.5		25.7	25.9
Sex					<.001		
Female	3,029	55.5	9,479	64.2		62.2	61.9
Male	2,426	44.5	5,291	35.8		37.8	38.1
Race/Ethnicity					<.001		
White	4,796	87.9	11,885	80.5		82.1	82.5
African American	190	3.5	1,217	8.2		7.2	7.0
Hispanic	120	2.2	379	2.6		2.5	2.5
Others	349	6.4	1,289	8.7		8.1	8.1
Geographic region					<.001		
North-East	1,113	20.4	2,885	19.5		20.0	19.8
South	1,267	23.2	3,779	25.6		24.8	25.0
North-Central	720	13.2	1,752	11.9		12.1	12.2
West	2,355	43.2	6,354	43.0		43.2	43.1
Rural/Urban							
Metro	4,525	83.0	12,172	82.4		83.3	82.3
Urban	815	14.9	2,278	15.4		14.7	15.5
Rural	115	2.1	320	2.2		2.0	2.2
Index year					<.001		
2003	584	10.7	1,255	8.5		9.0	9.1
2004	589	10.8	1,349	9.1		9.8	9.6
2005	586	10.7	1,280	8.7		9.4	9.3
2006	584	10.7	1,432	9.7		10.3	10.0
2007	610	11.2	1,569	10.6		10.7	10.8
2008	609	11.2	1,653	11.2		11.3	11.2
2009	623	11.4	1,888	12.8		12.3	12.4
2010	624	11.4	2,052	13.9		13.1	13.2
2011	646	11.8	2,292	15.5		14.2	14.5

Surveillance Epidemiology and End Results Program (SEER)-Medicare 2003–2011. Based on 5,455 Medicare beneficiaries with DLBCL and a random sample of 14,770 beneficiaries without any cancer who resided in SEER areas. Weighted percentages were derived with using inverse probability treatment weights.

Sig. significance level; *wt* weighted.

Appendix 2 | Adjusted Estimates from Negative Binomial Regression with Generalized Estimating Equation on Number of PCP Visits with Inverse Probability Treatment Weights Among Elderly with Diffuse Large B-Cell Lymphoma

	Number of PCP visits		
	β	*SE*	*p*
Time			
Baseline, T1	Ref.		
Prediagnosis, T2	0.133	0.016	<.001
Treatment, T3	0.491	0.028	<.001
Posttreatment, T4	0.027	0.022	.209
Short follow-up, T5	−0.121	0.02	<.001
Long follow-up, T6	−0.108	0.022	<.001
Age groups			
66–69	Ref.		
70–74	0.041	0.024	.087
74–79	0.046	0.025	.063
≥80	0.082	0.025	.001
Sex			
Female	0.059	0.017	.001
Male	Ref.		
Race			
Whites	Ref.		
African American	−0.065	0.04	.112
Hispanics	0.070	0.055	.202
Others	0.065	0.033	.056
Marital status			
Single	Ref.		
Married	−0.049	0.037	.196
Separated/Divorced/ Others	-0.036	0.039	.362
Region			
North-East	Ref.		
South	0.089	0.032	.003
North-Central	0.139	0.033	<.001
West	0.100	0.027	<.001
Rural/Urban			
Metro	Ref.		
Urban	0.044	0.027	.065
Rural	0.005	0.056	.854
DLBCL stage			
Stage I	Ref.		
Stage II	−0.020	0.023	.382
Stage III	−0.007	0.025	.808
Stage IV	0.030	0.021	.145
Radiotherapy			
Yes	0.085	0.023	<.001
No	Ref.		
Chemotherapy			
Yes	−0.025	0.024	.295
No	Ref.		
Immunotherapy			
Yes	0.099	0.028	<.001
No	Ref.		
Stem cell transplant			
Yes	−0.060	0.017	.001
No	Ref.		
Arthritis			
Yes	0.171	0.016	<.001
No	Ref.		
Diabetes			
Yes	0.209	0.016	<.001
No	Ref.		
Any heart condition			
Yes	0.295	0.016	<.001
No	Ref.		
Depression/Anxiety			
Yes	0.324	0.021	<.001
No	Ref.		
Asthma/COPD			
Yes	0.170	0.017	<.001
No	Ref.		
County% blacks			
1.14	Ref.		
4.21	−0.059	0.025	.051
9.46	−0.007	0.03	.931
28.38	−0.093	0.032	.005
County% hospitals			
0.56	Ref.		
0.96	0.024	0.025	.145
1.30	−0.001	0.024	.930
3.48	−0.038	0.028	.146
County% without health insurance			
12.89	Ref.		
17.21	0.015	0.025	.468
22.07	−0.048	0.03	.126
28.24	−0.074	0.033	.048
County average travel time			
19.50	Ref.		
24.09	−0.037	0.023	.104
27.42	−0.010	0.025	.632
31.06	−0.050	0.027	.043
County% less than high-school education			
8.27			
11.99	0.039	0.024	.137
15.75	0.082	0.028	.008
24.52	0.118	0.031	<.001

Surveillance Epidemiology and End Results Program (SEER)-Medicare 2003–2011. Based on 5,455 Medicare beneficiaries with DLBCL who had at least one PCP visit during T1 to T6. Adjusted beta coefficients and standard errors are from generalized estimating equation with negative binomial distribution and unstructured correlation matrix.*COPD* chronic obstructive pulmonary disease; *DLBCL* diffuse large B-cell lymphoma; *PCP* primary care physician.

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