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ORIGINAL PAPER

Care experiences among dually enrolled older adults with cancer: SEER-CAHPS, 2005–2013

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Abstract

Purpose Given the associations between poverty and poorer outcomes among older adults with cancer, we sought to understand the effects of dual enrollment in Medicare and Medicaid—as a marker of poverty—on self-reported care experiences among seniors diagnosed with cancer.
Methods Retrospective, observational study using cancer registry, Medicare claims, and care experience survey data (Surveillance, Epidemiology, and End Results [SEER]—Consumer Assessment of Healthcare Providers and Systems [CAHPS®]) for a national sample of fee-for-service (FFS) and Medicare Advantage (MA) enrollees aged 65 or older. We included people with one incident primary, malignant cancer diagnosed between 2005 and 2011, surveyed within 2 years after diagnosis ($n = 9{,}800$; 995 dual enrollees). Medicare CAHPS measures included 5 global ratings and 3 composite scores.
Results After adjustment for potential confounders, people with cancer histories who were dually enrolled were significantly more likely to report better experiences than non-duals on 2 measures (Medicare/their health plan: adjusted odds ratio [aOR]: 0.68, 95% confidence interval [CI] 0.53–0.87; prescription drug plan [PDP]: aOR: 0.54, 95% CI 0.40–0.73).
Conclusions Dual enrollees with cancer reported better experiences than Medicare-only enrollees in terms of their health plan (Medicare FFS or Medicare Advantage) and their PDP. Better ratings among dually enrolled beneficiaries suggest possible divergence between health outcomes and care experiences, warranting additional investigation.

Keywords Dual eligible · Poverty · Medicare · Medicaid · Cancer · Patient experience

Introduction

Poverty is a key social determinant of health [1] known to be associated with increased risk of delaying needed care, barriers to healthcare access, and higher morbidity and mortality [2]. Numerous cancer-focused studies have found significant disparities in access and outcomes between lower-income individuals and others [3]. People with lower incomes have lower cancer-screening rates [4], are more likely to be diagnosed at a later stage [5], are less likely to receive certain treatments [6, 7], and have lower cancer survival than higher-income people [8]. Lower-income individuals are also less likely to say that their physician explains things in a way they can understand and report less respect for their treatment preferences from their healthcare providers [9]. Even in countries with universal health insurance coverage, disparities in cancer care have been documented among people with lower incomes [10]. Understanding the experiences of cancer patients living in poverty is a priority for the National Cancer Institute [11].

Today, almost 10 million people are dually enrolled in Medicare and Medicaid in the US—about 1 in 5 Medicare beneficiaries—with 60% of dual enrollees being over age 65 [12]. Most dual enrollees have incomes below 200% of the Federal poverty level [13]. Compared to Medicare-only

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enrollees, dual enrollees tend to have more functional and cognitive limitations, and greater medical needs, than beneficiaries enrolled in Medicare or Medicaid alone [14]. Per-capita Medicare and Medicaid expenditures are substantially higher among dual enrollees than among non-duals [15].

As dual enrollees have minimal or no required co-payments/deductibles for covered medical services, dual coverage removes many financial barriers to care [15].Given known barriers associated with poverty, the dually enrolled population is at risk for receiving lower-quality medical care—a risk that may be exacerbated by increased needs to coordinate across two separate funding streams for Medicare and Medicaid [15]. At the same time, the additional coverage could result in better care from patients' perspectives.

In recent years, efforts to reward higher-quality healthcare have resulted in increasing emphasis on patient experiences. A decade ago, a seminal commentary from Berwick and colleagues laid out the Triple Aim of healthcare quality improvement: improving health outcomes, reducing healthcare costs, and improving the experience of care [16]. While definitions of "patient experience" vary, experts suggest that is a more specific measurement of patient care than satisfaction, referring to any observable process, either subjective or objective, reflecting specific components of care from the patient's perspective [17]. Previous research has begun to explore ways in which a cancer diagnosis may affect an individual's experiences of care [17–19], but it is unknown whether dual enrollment might also play a role in care experiences among people with cancer.

For this study, we used a new National Cancer Institute (NCI) and Centers for Medicare and Medicaid Services (CMS)-sponsored linkage of Surveillance, Epidemiology, and End Results (SEER) cancer registry data with CAHPS survey data and Medicare enrollment and claims data (SEER-CAHPS). Our goal was to explore associations between ratings of care and dual enrollment among older adults with a cancer history. Given both the risk factors for poor quality and the potential benefits of reduced cost sharing for dual enrollees, our research question was: Do older adults with a cancer history who are dual enrollees have worse or better experiences with overall care, personal doctor and specialist, and health and prescription drug plans, as well as getting needed care, getting care quickly, and physician communication, compared to individuals enrolled in Medicare only?

Methods

Data and population

Data available from the SEER-CAHPS linked data resource included (1) Medicare CAHPS data from surveys collected from a sample of Medicare enrollees between 1997 and 2013 to assess patient experiences with multiple aspects of their care, such as access to needed and timely care, doctor communication, and global ratings of their personal doctor, specialist, overall healthcare, Medicare and/or health plan, and prescription drug plan (PDP); (2) SEER registry data (diagnosis years 1973–2011) including cancer site, stage, initial treatment course (radiation/surgery), mortality, and patient sociodemographics; and (3) longitudinal Medicare claims data (2002–2013) on utilization and costs of care for FFS beneficiaries (~40% of the total sample).

The SEER cancer registry program, which began in 1973 and now covers approximately 30% of the US population, collects information on cancer incidence, survival, and other outcomes [20]. The Medicare CAHPS surveys, fielded annually since 1997, are national, probability-sample surveys of beneficiary experience. Through these surveys, CMS collects and publicly reports a variety of measures of patient experiences with care. The surveys are administered by mail in English and Spanish (and in Chinese for MA, since 2012), with a second mailing and bilingual telephone follow-up for non-respondents [21]. Response rates vary by survey type and year, ranging from 36 to 84%, with more recent years having lower rates [22]. Individuals residing in institutions such as nursing homes are not included in the survey. The CAHPS surveys are some of the most widely used instruments for measuring US healthcare quality [23].

Cohorts

We used SEER-CAHPS data to study dual enrollees and other enrollees with cancer histories. Cancer status was determined by SEER; we stratified the cohort into breast, colorectal, lung, prostate, and all other cancers using International Classification of Diseases—Oncology codes.

Given the possible differences in reasons for coverage among individuals covered by Medicare for disability-related rather than age-related reasons and differences in cancer diagnosis distribution related to age, we limited our sample selection to individuals aged 65 and over at diagnosis. Inclusion in the dual group was ascertained using two variables: a monthly flag variable from SEER which indicates that the beneficiary received Medicaid or other state assistance to low-income individuals, known as the state buy-in (SBI) variable*;* and a SEER-CAHPS constructed variable which includes additional information on dual status coverage from Medicare at time of survey [24]. Unfortunately, neither variable provides further details on partial vs. full dual benefits.

Inclusion/exclusion criteria

The cancer cohort included those aged 65+ at the time of their cancer diagnosis, with one primary, malignant cancer reported to a SEER registry between 2005 and 2011, who survived at least six months post-diagnosis, responded to a Medicare CAHPS survey within 2 years of diagnosis (between 2007 and 2013), and were continuously enrolled in Medicare (either FFS or MA) during the study period, defined as the first day of the month of diagnosis until the survey-received date. We restricted the sample to those with surveys in 2007–2013 to improve consistency in survey items across the study period. We excluded five individuals who had missing data for race and eight males with breast cancer. Our final cancer cohort ($n = 9{,}800$) included 995 dual enrollees and 8,805 enrollees with Medicare only (Online Resource 2, Fig. S1).

Measures

Our dependent variables, taken from the Medicare CAHPS survey instrument, consisted of both global ratings and composite scores. Global ratings of overall care, personal doctor, specialist, Medicare or health plan, and PDP are scored from 0 to 10, with the endpoints labeled (e.g., for the overall care item, 0 = worst health care possible and 10 = best health care possible). Composites (doctor communication, getting needed care, and getting care quickly) are made up of varying numbers of individual items that are rated never, sometimes, usually, or always. Scores on items in the composite are combined using equal weights. Linear mean scores are then transformed to a 0–100 scale (100 = highest). The surveys ask respondents to consider the care they received within the prior 6 months. Most beneficiaries were sampled for and responded to only one survey within the study timeframe; for the few respondents who had multiple survey responses in our sample, we selected responses from the survey closest to their cancer diagnosis date.

Responses were skewed; for example, the median on each composite score was 100 (out of 100), and for the single-item global rating of personal doctor and specialist, the median value was 10 (out of 10). We dichotomized global ratings into 0–8 (“lower ratings”) compared with 9 or 10 (“top ratings”), and 0–89 compared with 90–100 on composite scores [25–27]. We used logistic regression of dichotomized outcomes to focus on comparisons between groups of different raters based on the measure distributions. We tested other approaches, including linear regression on mean scores and ratings, and found comparable results (Online Resource 1, Fig. S1). Given the distribution of the rating scores, we report only the logistic regression results in this paper.

Respondents self-reported general and mental health status as excellent, very good, good, fair, or poor. Prior studies by the researchers who developed these items suggest that intervals between the item responses are not uniform [28, 29]. Thus, we dichotomized the measures into fair/poor vs. all other options.

Statistical analyses

We analyzed the sample sociodemographic characteristics by group (dual or other). We used person-level weights supplied with the data to generate weighted proportions that reflect the overall population used for the sampling frame for each survey (state for FFS surveys; health plan for MA surveys) [30]. To account for the survey design, we used the Taylor-linearized variance method to estimate the standard errors.

We examined rates of missing data and chose to specify “missing” as an analytic category where appropriate (see Online Resource 3 for more details). Next, we estimated survey-weighted multivariable logistic regression models for each CAHPS measure, with the exposure variable being dual status. Because of the relatively small sample size, we aimed for parsimony in selecting covariates that could affect the outcomes. The following independent variables were in every set of models: patient sociodemographic characteristics (age category [65–69, 70–74, 75–79, and 80–84; ref: 85 +], sex, race/ethnicity [Black, Asian, Hispanic of any race, other race; ref: non-Hispanic white], educational attainment [ref: less than high school; high school/GED/some college or 2-year degree; 4-year college graduate or higher]); two measures of self-rated health status (fair or poor general health and mental health vs. all other response options); geographic characteristics (Census region [Northeast, Midwest, and South; ref: West]), urbanicity of county of residence (urban area; ref: rural area]); MA enrollment; proxy assistance (yes vs. all other response options); self-reported number of chronic conditions (2 + vs. all other options); cancer site (female breast, colorectal, lung, prostate; ref: all others) stage at diagnosis (in situ, regional, distant, unknown/unstaged; ref: local), time in months since diagnosis, marital status (married vs. ref: non-married) and living in a high-poverty neighborhood ($> 20\%$ vs. ref: $\leq 20\%$). Neighborhood poverty characteristics, based on household income as a percentage of the Federal poverty level and derived from information obtained in the 2010 Census, are supplied as a standard analytic variable in SEER-CAHPS.

Significance levels depended on the analysis, since we applied a Bonferroni correction for each analysis (dividing 0.05 by the number of comparisons). Analyses were conducted in SAS v. 9 (SAS Institute Inc., Cary, NC) and Stata/MP v. 14.1 (StataCorp LP, College Station, TX).

Results

Sociodemographic and clinical characteristics

In Table 1, we present sociodemographic characteristics by dual status. Dual enrollees were significantly more

Table 1 Sociodemographic characteristics and health status of Medicare beneficiaries over age 65 with and without cancer, by dual status. *Source* Authors' analysis of SEER-CAHPS data, 2005–2013.

Characteristic	Dual (unweighted n = 995)	Non-dual (unweighted *n* = 8,805)	*p*
Percent of weighted sample	7	93	
Enrolled in Medicare advantage	17	19	0.124
Age			0.732
65–69	26	24	
70–74	29	28	
75–79	21	22	
80–84	15	17	
85+	9	8	
Female sex	57	44	**< 0.001**
Race/ethnicity			**< 0.001**
White	60	90	
Black	21	5	
Asian/Pacific Islander	9	1	
Hispanic	8	1	
Other/multiple	2	3	
Married	34	62	**< 0.001**
Missing/unknown marital status	9	9	
Neighborhood poverty level			**< 0.001**
< 5%	9	28	
5 to < 10%	20	29	
10 to < 20%	31	27	
20% +	36	14	
Missing/unknown	4	2	
Rural residence	5	2	0.004
Census region			**< 0.001**
Northeast	11	19	
Midwest	5	12	
South	30	21	
West	53	48	
Educational attainment			**< 0.001**
< 12 years	49	13	
12–15 years	32	52	
16 + years	9	27	
Missing/unknown	10	8	
Self-rated general health status			**< 0.001**
Excellent/very good/good	44	64	
Fair/poor	51	32	
Missing/unknown	6	4	
Self-rated mental health status			**< 0.001**
Excellent/very good/good	76	88	
Fair/poor	19	8	
Missing/unknown	5	4	
Proxy respondent or assistance	28	10	**< 0.001**
Missing/unknown proxy status	26	22	

Percentages shown are weighted estimates that represent the sampling frame (state for fee-for-service respondents, plan for Medicare Advantage respondents). *p* values, estimated using Pearson's chi-squared tests, identify statistically significant unadjusted differences between weighted percentages of the dual and non-dual samples. Significant values are bolded, with significance defined as $p < 0.004$ after Bonferroni corrections for multiple comparisons likely than other enrollees to be female, non-white, and single, have only a high-school education or less, live in the South or West, have a proxy respondent or assistance, live in a high-poverty area, and report fair/poor general and mental health status. There were no significant differences between dual enrollees and others in terms of MA enrollment or age (Table 1).

In Table 2, we provide clinical characteristics stratified by dual status and sex. About 31–36% of the female respondents had breast cancer, and 46–52% of the men had prostate cancer; 52–64% of respondents had local disease at diagnosis, with female dual enrollees having the lowest proportion of local disease. Dual enrollees differed from others with regard to cancer sites and stages, as well as the proportion reporting various chronic conditions. The mean number of months between cancer diagnosis and survey response was 13.9 months for dual enrollees and 13.7 months for others ($p = 0.4875$; not shown).

Adjusted logistic regression results

Table 3 summarizes the survey-weighted multivariable logistic regression results. Dual enrollees with cancer were significantly less likely than non-duals with cancer to report worse experiences with Medicare/health plan (adjusted OR [aOR]: 0.66, 95% confidence interval [CI] 0.51–0.85) and PDP (aOR 0.42, 95% CI [0.30–0.60]). Few predictors aside from dual enrollment were significantly associated with care experiences. However, having fair/poor self-reported physical or mental health was associated with worse experiences on almost every measure; with worse self-reported health, odds of worse ratings increased.

Discussion and conclusions

In this study, we found that older adults with a cancer history who are dually enrolled are more likely to report top ratings for Medicare/health plan and PDPs than other seniors. The additional financial support provided to dual enrollees—in the form of waived premium and minimal

Table 2 Clinical characteristics of Medicare beneficiaries over age 65 with cancer, by dual status and sex ($N = 9{,}800$). *Source* Authors' analysis of SEER-CAHPS data, 2005–2013

Group	Dual		Non-dual		Group-level *p*
Subgroup	Male	Female	Male	Female	
Unweighted n	420	575	4,901	3,904	
Weighted percentage	43%	57%	56%	44%	**< 0.001**
Cancer site					**0.004**
Breast	0%	31%	0%	36%	
Colorectal	13%	18%	9%	11%	
Lung	8%	9%	7%	8%	
Prostate	52%	0%	46%	0%	
Other	27%	41%	38%	44%	
Tumor stage at diagnosis					**< 0.001**
In situ	2%	0%	6%	3%	
Local	64%	52%	61%	55%	
Regional	15%	26%	14%	22%	
Distant	8%	13%	10%	11%	
Unknown/unstaged	4%	4%	3%	2%	
Missing	7%	4%	6%	7%	
Specific conditions reported					
Heart attack, coronary heart disease, or angina	33%	33%	36%	21%	0.285
Stroke	17%	20%	10%	9%	**< 0.001**
Asthma or emphysema/COPD	24%	32%	21%	20%	**0.003**
Diabetes or high blood sugar	43%	45%	33%	26%	**< 0.001**
Current smoker	22%	15%	7%	5%	**< 0.001**

Percentages shown are weighted estimates that represent the sampling frame (state for fee-for-service respondents, plan for Medicare Advantage respondents). *P* values, estimated using Pearson's chi-squared tests, identify statistically significant unadjusted differences between dual and non-dual enrollees. Significant values are bolded, with significance defined as $P < 0.006$ after Bonferroni corrections for multiple comparisons. CHD: coronary heart disease; COPD: Chronic obstructive pulmonary disease

Table 3 Summary of multivariable survey-weighted logistic regression models predicting likelihood of lower ratings/scores on each outcome among Medicare CAHPS respondents with and without cancer. *Source* Authors' analysis of SEER-CAHPS data, 2005–2013

	Model *N*	Effect of dual enrollment: aOR	(95% CI)	Independent predictors aside from dual status associated with reporting worse experiences
Global ratings below 9 out of 10				
Overall care	8,260	1.06	(0.82–1.38)	Poor/fair GHS Poor/fair MHS
Personal doctor	7,542	1.20	(0.90–1.60)	Poor/fair MHS
Specialist	6,773	1.05	(0.75–1.47)	Poor/fair GHS
Medicare/health plan	8,773	**0.66**	**(0.51–0.85)**	16 + years education
Prescription drug plan	6,538	**0.42**	**(0.30–0.60)**	MA enrollment Male sex Poor/fair GHS Proxy respondent
Composite scores below 90 out of 100				
Getting needed care	7,833	1.08	(0.83–1.41)	Poor/fair GHS Poor/fair MHS
Getting care quickly	8,161	1.01	(0.78–1.31)	Poor/fair GHS Poor/fair MHS
Doctor communication	7,606	1.05	(0.80–1.38)	Poor/fair MHS

Shown are the adjusted odds ratios (aORs) and 95% confidence intervals (CIs) for the independent association between dual enrollment and lower ratings on each of the 8 patient experience measures we examined (below 9 out of 10 for global ratings and below 90 out of 100 on composite scores). The column with other independent predictors shows variables aside from dual status that showed a significant, independent association between the listed characteristic and higher odds of lower ratings. Statistical significance was set at $P < .006$ to account for multiple comparisons; significant aORs (95% CIs) are bolded

All models adjusted for MA enrollment, age category (65–69, 70–74, 75–79, 85 + [reference]), sex, race/ethnicity (Black, Asian, Hispanic, other race, White [reference]), educational attainment category (< 12 years [reference], 12–15 years, 16 + years), Census region (Northeast, Midwest, South, West [reference]), metropolitan area (vs. rural), self-reported general and mental health status (fair/poor vs. all other response options), proxy response (yes vs. all other options), self-reported number of chronic conditions (2 + vs. all other response options), marital status (married vs. all other response options), neighborhood poverty level of 20% or more (vs. all other response options), cancer stage at diagnosis (unknown, in situ, local [reference], regional, or distant), and whether the individual was diagnosed with breast, prostate, lung, colorectal, or some other kind of cancer

aOR adjusted odds ratio, *CI* confidence interval, *GHS* general health status (), *MHS* mental health status, *MA* Medicare Advantage

co-payment/co-insurance requirements—likely means that dual enrollees with cancer have lower out-of-pocket burden [31]. One possibility is that the extra financial support promotes better experiences of care for those dually enrolled compared with seniors who have to pay more out-of-pocket for their coverage. Results could also be explained by differences in expectations of care, unmeasured confounding across duals and non-duals (for example, differences in cost sharing), or differences in response tendencies (such as socially desirable responding, yea-saying, or nay-saying) in different groups [21, 32].

In addition, these results could be explained by more frequent encounters with the healthcare system, as familiarity with healthcare plans and providers might engender more positive experiences and allow more opportunities to meet perceived needs. While we attempted to investigate this possibility empirically (Online Resource 1), our findings were limited by small samples. Future studies with larger samples are needed to confirm these exploratory results.

Individuals with lower incomes are at higher risk for lower-quality care, reduced access to care, and poorer outcomes [33–36]. However, in this study, we find evidence that dual-enrolled seniors with cancer, on average, rate their overall experience with care *similarly* to other seniors with cancer, after adjusting for potential confounders. More research is needed to better understand the connection between structure, process, and outcome quality measures and care experiences among people with a cancer history.

Previous studies have investigated whether dual enrollment is associated with differences in cancer-related outcomes [6, 31, 36]. In one study of beneficiaries with lung cancer, dual enrollees were half as likely to undergo resection; among those who did receive surgery, duals had worse survival than non-duals, but survival was the same for duals and non-duals who did not undergo surgery [6]. Dual enrollees have been shown to be less likely to receive chemotherapy, even after adjusting for cancer site, stage, and comorbidity [31]. Thus, finding better ratings of care among people with cancer who were dually enrolled suggests possible divergence between health outcomes and patient experience and warrants additional investigation.

Our research is in line with prior research that showed significantly higher patient experience ratings on some measures for low-income Medicare beneficiaries overall. Specifically, individuals deemed eligible for a low-income subsidy have been previously reported to have more positive experiences with their health plan or Medicare and/or PDP [21]. Prior research has also shown that older individuals, those with better self-perceived health, and those with less education provide more positive evaluations, on average [37, 38]. Our study adds a new dimension to previous work, in that our focus was to understand how people with a cancer history specifically rate their care. Individuals with cancer histories—many of whom also have substantial comorbidity burdens—have greater needs for care and ongoing surveillance; thus, the NCI is invested in studying their care quality. Moreover, nearly 1 in 10 Medicare FFS dollars goes to cancer treatment and screening, and more than half of new cancer cases each year occur in people over age 65 [39].

Many factors drive patient experience, and some of those factors were unavailable in our data (for example, co-payments and co-insurance). Moreover, the data we used to identify dual status unfortunately provided no information regarding benefit levels (i.e., full or partial dual eligibility). Further, the duals group included 28% with a proxy respondent or assistance and another 26% with missing or unknown proxy status. Elliott and colleagues [40] previously reported that proxy respondents rate care experiences less positively than non-proxies, by an average of 0.21 standard deviations; given this, our estimates may be conservative.

Our sample was limited to older individuals (ages 65 +) residing in SEER areas, with about half the sample residing in western states. While the weights provided with the data allowed us to make nationally representative estimates and correct for non-response bias, our results may not be generalizable beyond the study population and are limited by the relatively low response rates to the Medicare CAHPS surveys [22].

Additionally, a limitation of the CAHPS outcome measures is that they are skewed, which reduces the amount of variation in the scores and ratings. For example, means on the five global ratings ranged from 8.0 to 9.1, regardless of cohort, group, or covariate adjustment. We addressed this by using dichotomized measures, which, while having their own limitations, allow us to focus on the proportion who gave lower ratings or scores—ranging from 14 to 53%—and provide more variation in the outcomes. Dichotomous measurement also allows us to identify a clearly defined population as the focus of interventions to improve patient experience; does not assume uniformity between intervals of the scale (assuming 0 to 5 is the same "distance" as 5 to 10); avoids confusion between 0–10 and 0–100 scales; and is easier to interpret. Although we feel logistic models have multiple advantages over linear for this study, we did estimate linear models for our sensitivity analyses, with only a few differences seen in the results (see Online Resource 1).

Our findings suggest that, after adjustment for potential confounders, patient-reported care quality is similar for dual-enrolled seniors with cancer and other seniors overall, with small but significant differences on two measures (Medicare/health plan and PDP). Whether ratings represent differences in care quality or other differences in patient experience, despite similar care quality, is unknown. Better ratings of Medicare/health and drug plans may reflect lower cost-sharing burdens among dual enrollees. Future studies, including those with direct observation and mixed methods, are needed to better understand the drivers of patient experience among people with cancer.

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Compliance with ethical standards

Conflict of interest The authors declare no conflicts of interest.

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