Unveiling SEER-CAHPS®: A New Data Resource for Quality of Care Research

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BACKGROUND: Since 1990, the National Cancer Institute (NCI) and Centers for Medicare and Medicaid Services (CMS) have collaborated to create linked data resources to improve our understanding of patterns of care, health care costs, and trends in utilization. However, existing data linkages have not included measures of patient experiences with care.

OBJECTIVE: To describe a new resource for quality of care research based on a linkage between the Medicare Consumer Assessment of Healthcare Providers and Systems (CAHPS®) patient surveys and the NCI's Surveillance, Epidemiology and End Results (SEER) data.

DESIGN: This is an observational study of CAHPS respondents and includes both fee-for-service and Medicare Advantage beneficiaries with and without cancer. The data linkage includes: CAHPS survey data collected between 1998 and 2010 to assess patient reports on multiple aspects of their care, such as access to needed and timely care, doctor communication, as well as patients' global ratings of their personal doctor, specialists, overall health care, and their health plan; SEER registry data (1973–2007) on cancer site, stage, treatment, death information, and patient demographics; and longitudinal Medicare claims data (2002–2011) for fee-for-service beneficiaries on utilization and costs of care.

PARTICIPANTS: In total, 150,750 respondents were in the cancer cohort and 571,318 were in the non-cancer cohort.

MAIN MEASURES: The data linkage includes SEER data on cancer site, stage, treatment, death information, and patient demographics, in addition to longitudinal data from Medicare claims and information on patient experiences from CAHPS surveys.

KEY RESULTS: Sizable proportions of cases from common cancers (e.g., breast, colorectal, prostate) and short-term survival cancers (e.g., pancreas) by time since diagnosis enable comparisons across the cancer care trajectory by MA vs. FFS coverage.

CONCLUSIONS: SEER-CAHPS is a valuable resource for information about Medicare beneficiaries' experiences of care across different diagnoses and treatment modalities, and enables comparisons by type of insurance.

INTRODUCTION

Since 1998, the Centers for Medicare and Medicaid Services (CMS) has sponsored annual administrations of the Consumer Assessment of Healthcare Providers and Systems (CAHPS®) surveys to assess the health care experiences of Medicare enrollees in Medicare Advantage (MA) and fee-for-service (FFS) health plans.[1] Previous studies have used data from these surveys to assess differences in patient experiences by plan types (i.e., MA vs. FFS), racial/ethnic groups, and care delivery setting (e.g., hospital inpatient, outpatient, nursing home).[2–7] Existing research has also examined the experiences of specific subgroups of patients, such as those with depression or kidney disease.[8,9] However, to date, the CAHPS measures have had limited use in assessing the experiences of patients with cancer.

Currently, there are approximately 13.7 million cancer survivors in the United States.[10,11] The prevalence of cancer is projected to grow significantly in the future, given improvements in detection and treatment, and the growing size of the population aged 65 and older.[10–12] Furthermore, the process of receiving appropriate cancer care is often complex, time-consuming, expensive, and fraught with administrative barriers.[13–16] Due to these complexities, the Institute of Medicine (IOM) and the National Cancer Institute (NCI) have released several reports that emphasize the importance of patient-centered care in the treatment of cancer patients and the use of patient-centered measures to evaluate the quality of care that these patients receive.[13,14,17,18]

This paper describes a new data set that links data from Surveillance, Epidemiology and End Results (SEER) with

CAHPS Medicare survey data and results from a collaborative effort between NCI, the SEER registries, and CMS. These data provide a rich opportunity for analyses of Medicare beneficiaries' experiences with their care at various stages of the cancer care continuum, including: the initial year after diagnosis, when patients are most likely to receive cancer treatments; the years of post-treatment follow-up care; those of long-term cancer survivorship; and the final end-of-life care phase. Analyses from these data have the potential to fill an important gap in existing knowledge by enabling comparisons of patients' care experiences between MA and FFS beneficiaries and between patients with and without cancer. For Medicare FFS beneficiaries, the SEER-CAHPS data set also allows for the evaluation of their health care utilization and costs of care.

METHODS

Data Sources

Four principal sources of data comprise the linked SEER-CAHPS data set: 1) CAHPS data for all Medicare MA and FFS beneficiaries between 1998 and 2010; 2) SEER data for CAHPS survey respondents with cancer living in a SEER region; 3) Medicare claims data for all FFS beneficiaries who were CAHPS survey respondents; and 4) Medicare Enrollment Database (EDB) eligibility and demographic data for all CAHPS survey respondents.

CAHPS. The CAHPS program began in 1995 and has produced a suite of survey and reporting kits to assess patient experiences with health care in the United States.[19] CMS has sponsored annual administration of CAHPS surveys to Medicare MA beneficiaries since 1998 and to FFS beneficiaries since 2001. The CAHPS Medicare-stratified sampling methodology is discussed in detail by Zaslavsky et al. (2012).[20] Surveys are distributed by mail with telephone follow-up of non-respondents. The CAHPS Medicare surveys assess patient reports of multiple aspects of their care and include multi-item composites to summarize reports, which are described below:

- Getting needed care

  – How often was it easy to get appointments with specialists?
  – How often was it easy to get the care, tests, or treatment you thought you needed through your health plan?

- Getting care quickly

  – When you needed care right away, how often did you get care as soon as you thought you needed?
  – Not counting times you needed health care right away, how often did you get an appointment for your health care at a doctor's office or clinic as soon as you thought you needed?
  – How often did you see the person you came to see within 15 min of your appointment time?

- Doctor Communication

  – How often did your personal doctor explain things in a way that was easy to understand?
  – How often did your personal doctor listen carefully to you?
  – How often did your personal doctor show respect for what you had to say?
  – How often did your personal doctor spend enough time with you?

- Health plan customer service

  – How often did your health plan's customer service give you the information or help you needed?
  – How often did your plan's customer service staff treat you with courtesy and respect?

The surveys also elicit global ratings of the personal doctor, specialists, overall health care, and the health plan. While some CAHPS items have changed over time, the core concepts assessed remained fairly constant. CAHPS surveys also collect information on a variety of patient characteristics, including: age, gender, race/ethnicity, education, smoking status, general health status, comorbid health conditions (e.g., heart disease, stroke, diabetes, chronic obstructive pulmonary disease), language of the survey (English or Spanish), and proxy assistance. In addition, CAHPS surveys field quality of life measures, including SF-36 measures of physical and mental health for certain years.

SEER. The SEER program collects incidence and survival information for all new cancer cases in defined U.S. geographic areas, with a unique case identification number for each patient. The SEER program began in 1973 and now covers approximately 28 % of the U.S. population, with data from nine states (California, Connecticut, Iowa, New Mexico, Utah, Hawaii, Kentucky, New Jersey, and Louisiana) and from selected regions in Georgia, Michigan, and Washington.[21,22] SEER collects demographic and disease-specific information on cancer patients, including: age, gender, race/ethnicity, marital status, month and year of diagnosis, primary tumor site, tumor morphology, and stage. SEER registries also collect data on treatment, including surgical and radiation treatments provided as the first course of therapy.

Medicare Claims. For Medicare FFS beneficiaries who responded to the CAHPS surveys, we obtained Standard Analytic Files from CMS: Inpatient, Outpatient, Hospice, and Home Health Agency. We also obtained the National Claims History (NCH) Durable Medical Equipment file and the Carrier file, which contains claims submitted by non-institutional providers such as physicians, physician assistants, and nurse practitioners. For inpatient information, including hospital and skilled nursing facilities, we used the Medicare Provider Analysis and Review file. All of these claims files contain diagnosis codes, procedure codes, dates of service,

provider information, service charges, and Medicare payments. All files include a health insurance claim number (HICN) for each beneficiary that can be used to identify the same beneficiary across files. Notably, claims files were not available for Managed Care beneficiaries.

Medicare Enrollment Database (EDB). The EDB is the master file that contains enrollment and entitlement data for all Medicare beneficiaries. For each CAHPS respondent, we obtained the following information: Part A and Part B coverage, HMO enrollment, third-party payer of premiums in either Part A or Part B, Medicaid enrollment, disability status, state of residence, age, gender, race/ethnicity, date of birth, and date of death (if applicable).

File Linkage

We identified beneficiaries who responded to the CAHPS FFS or MA surveys between 1998 and 2010, and linked them to the SEER data and Medicare claims, for FFS beneficiaries. To determine if a survey was taken in a SEER region, we compared the date the CAHPS survey was received with the respondent's location at that time. For surveys from 2007 to 2010, we have the exact date of survey receipt; for earlier years, we imputed a receipt date using the midpoint of the survey collection interval range. Respondents with at least 1 day of residence in a SEER state in the year the survey was received or in the year immediately prior were identified as residing in a SEER state. Because some surveys were administered early in a given year and the CAHPS Medicare items ask about care received in the previous 6 months, we included a 1-year look-back period to obtain a more comprehensive understanding of respondents' care experiences.

To link CAHPS respondents to the SEER data, we used a prior linkage of persons in SEER who had been matched to Medicare enrollment to create the SEER-Medicare data. As part of the SEER-Medicare linkage, the SEER cancer registries send individual identifiers for all persons in their files to be matched against Medicare's master enrollment file. The resulting file contains the SEER case number paired with the person's HICN. CAHPS respondents included in the SEER data were designated as the cancer group. We defined a comparison group that consisted of all Medicare beneficiaries who did not have cancer (as defined by our SEER linkage), but who did have at least 1 day of residence in a SEER region either in the year that they completed the CAHPS survey or in the year prior. Data from beneficiaries who did not have cancer according to SEER data and did not reside in a SEER region in the year of or the year prior to the survey were excluded from this comparison group, but their information was retained in the data set. For all CAHPS FFS respondents, we obtained and linked Medicare claims from CMS for all available years (i.e., 2002–2011). We anticipate the SEER-CAHPS data set will be publicly available to researchers in late 2016.

Data Description and Analysis

In order to describe the strengths and the scope of the SEER-CAHPS data set, we conducted several descriptive analyses, examining specific subgroups that may be of interest to researchers. We identified the number of CAHPS respondents classified as having cancer, the number of those without cancer, and those who lived and did not live in a SEER region during the time of the survey. For each of these groups of respondents, we calculated the proportion who took the MA and FFS surveys for each survey year.

After looking at the overall sample, we then conducted further analyses focused on the cancer and non-cancer comparison groups. We describe several key characteristics of the respondents in these two groups, stratified by insurance type. The majority of the variables from CAHPS that are presented in this paper were collected from single survey items: gender, race/ethnicity, education, Spanish survey, and general health status. For the race/ethnicity variable, patients of Hispanic origin received a Hispanic classification regardless of other race status. Smoking behavior and proxy assistance were both constructed from multiple survey items.[23]

Age was derived using the date that the survey was received by CMS and the respondent's date of birth as it appeared on the EDB. SEER region was based upon the date of survey receipt and was taken from the year in which the survey was received for both the cancer and non-cancer groups. For 99 % of these respondents, SEER region status in the survey year remained unchanged from the prior year.

SEER data include multiple measures of cancer stage. We report results based on SEER historic stage, which includes the following categories: In situ; localized; regional; distant; or unstaged. Prostate cancer is the only cancer that uses the "localized/regional" combined category. Treatment data from SEER indicates if the patient's initial course of therapy included surgery, radiation, or both. Given the incomplete ascertainment of chemotherapy data by SEER registries, chemotherapy is not included in the public-use SEER data.

For researchers interested in specific cancers, we conducted stratified analyses by FFS and MA and identified the total number of respondents for 19 different cancer types. For each cancer, we identified the timing of the CAHPS survey with respect to date of cancer diagnosis (i.e., prior to first cancer diagnosis, within 2, 3–5, 6–10, and 11+ years after diagnosis). It should be noted that these time points were chosen to capture multiple phases in the cancer care trajectory, but can be grouped differently (e.g., diagnosed within 1 year). For the four most prevalent cancers (breast, prostate, colorectal, and lung), we conducted stratified analyses by FFS/ MA status and present the number of cases by time since diagnosis for each cancer stage and by initial treatment type (i.e., surgery, radiation, or both) (Appendix Tables 7, 8 and 9).

In total, the analytic file contains data from 3,059,747 Medicare beneficiaries, representing 3,383,661 CAHPS surveys taken between 1998 and 2010. The number of surveys exceeds the number of individual beneficiaries, because a

small percentage of respondents answered the survey multiple times. For those with multiple surveys, we analyzed only their first survey taken.

RESULTS

Figure 1 provides information on the number of respondents in the SEER-CAHPS data set by their cancer status, SEER status, and insurance plan (FFS/MA) at the time of the survey. For respondents in the cancer group, Figure 1 provides information on the number of individuals who took surveys either before or after their first cancer diagnosis. The average annual CAHPS response rate was 71 % (Appendix Table 5).

Table 1 provides information on variables and topic areas in the data set. Table 2 presents information on demographic characteristics and health status, stratified by cancer status and Medicare coverage (MA/FFS). In total, the sample residing in the SEER area includes 150,750 individuals with cancer and 571,318 individuals without cancer with similar proportions of MA (65 %) and FFS surveys (35 %) in each group. A greater proportion of respondents with cancer were 75 years and older, and male, relative to those without cancer among both MA and FFS beneficiaries. Race/ethnicity and education levels were similar between groups, although higher proportions of minorities were in the non-cancer cohort for both MA and FFS insurance types. FFS respondents had a higher percentage of dual eligibles (i.e., those with Medicare and Medicaid) compared to those with MA coverage for both the cancer (13 vs. 6 %) and non-cancer (21 vs. 11 %) cohorts. Health status and smoking status were similar between the cancer and non-cancer cohorts and across insurance types.

Table 1. Overview of Variables in SEER-CAHPS Data Linkage

Variables	SEER	Medicare data (Claims/Enrollment Files)	CAHPS
Cancer Site	✓		
Cancer Stage	✓		
First course of treatment	✓		
Vital status		✓	
Cause of death	✓	✓	
Costs of care & service utilization		✓	
Inpatient claims		✓	
Outpatient claims		✓	
Hospice claims		✓	
Home health claims		✓	
Patient experiences			✓
Reports about care			✓
Global ratings of care			✓
Patient case mix variables			✓
Patient demographics	✓	✓	✓
Health-related quality of life measures			✓

Tables 3 and 4 provide information for MA and FFS respondents by cancer type and time since diagnosis. For the most common cancers (i.e., prostate, breast, colorectal), there are relatively large sample sizes at each of the major time periods post-diagnosis. Across each individual type of cancer, most surveys were taken after the first cancer diagnosis and provide sizable proportions of cases diagnosed within 2, 3–5, 6–10, and 11 or more years. For example, among individuals with colorectal cancer covered by MA insurance, there are between 1652 and 2535 cases at each of these time points (Table 3). Among their FFS counterparts, there are between 868 and 1608 colorectal cancer cases (Table 4).
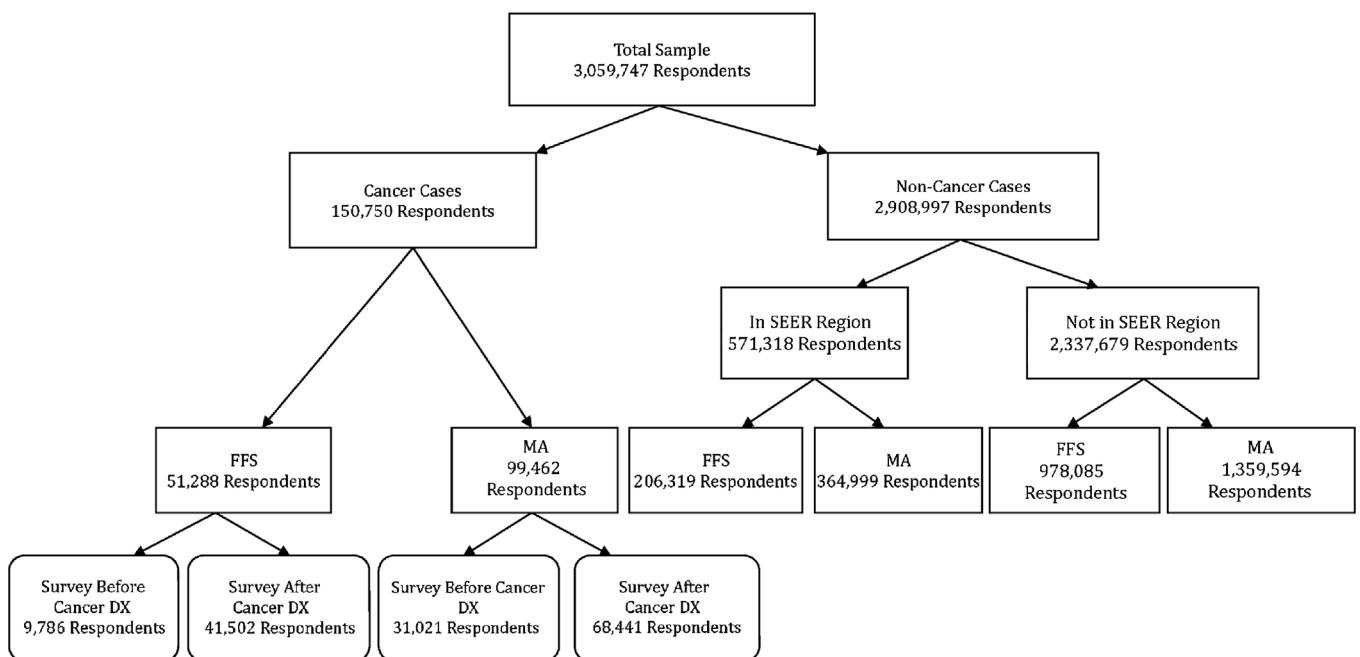

Figure 1. Number of cancer and non-cancer survey respondents by SEER region and SEER-CAHPS plan type (1998–2010).

Table 2. Demographic Characteristics of CAHPS respondents residing in SEER Areas by Program Type: 1998–2010

Demographic characteristics	Cancer (*n*=150,750)					Non-cancer (*n*=571,318)				
	Total	MA		FFS		Total	MA		FFS	
		N	*%*	*N*	*%*		*N*	*%*	*N*	*%*
		99,462	66.0	51,288	34.0		364,999	63.9	206,319	36.1
Age										
Under 65	6972	3801	3.8	3171	6.2	59,212	29,641	8.1	29,571	14.3
65–74	67,607	46,300	46.6	21,307	41.5	277,612	183,967	50.4	93,645	45.4
75–84	59,121	38,888	39.1	20,233	39.4	181,451	119,028	32.6	62,423	30.3
85+	17,050	10,473	10.5	6577	12.8	53,043	32,363	8.9	20,680	10.0
Gender										
Male	74,358	49,511	49.8	24,847	48.4	232,183	148,006	40.5	84,177	40.8
Female	76,392	49,951	50.2	26,441	51.6	339,135	216,993	59.5	122,142	59.2
Race/ethnicity										
White	115,086	74,532	74.9	40,554	79.1	394,900	247,190	67.7	147,710	71.6
Black	8554	5852	5.9	2702	5.3	38,203	24,492	6.7	13,711	6.6
Other	1012	789	0.8	223	0.4	4024	2966	0.8	1058	0.5
Asian	6115	4395	4.4	1720	3.4	32,620	22,304	6.1	10,316	5.0
Hispanic	9063	6772	6.8	2291	4.5	53,374	37,721	10.3	15,653	7.6
North American Native	494	308	0.3	186	0.4	2587	1357	0.4	1230	0.6
Mixed, non-Hispanic	2175	1370	1.4	805	1.6	10,132	6033	1.7	4099	2.0
Unknown	8251	5444	5.5	2807	5.5	35,478	22,936	6.3	12,542	6.1
Education										
Did Not Complete High School	32,673	22,414	22.5	10,259	20.0	135,624	87,765	24.0	47,859	23.2
High School Graduate or GED	45,398	30,004	30.2	15,394	30.0	171,448	109,591	30.0	61,857	30.0
Some College/2-years Degree	33,859	22,835	23.0	11,024	21.5	127,106	83,048	22.8	44,058	21.4
4-years College Graduate	13,551	8405	8.5	5146	10.0	45,153	27,713	7.6	17,440	8.5
More than 4-years College Degree	16,019	9657	9.7	6362	12.4	53,830	31,988	8.8	21,842	10.6
Unknown	9250	6147	6.2	3103	6.1	38,157	24,894	6.8	13,263	6.4
Dual medicare-medicaid eligible										
No	138,284	93,419	93.9	44,865	87.5	488,722	326,382	89.4	162,340	78.7
Yes	12,466	6043	6.1	6423	12.5	82,596	38,617	10.6	43,979	21.3
Health characteristics-smoking										
Non Smoker or Former Smoker	127,301	83,632	84.1	43,669	85.1	478,481	307,811	84.3	170,670	82.7
Current Smoker	14,999	10,282	10.3	4717	9.2	59,326	35,700	9.8	23,626	11.5
Unknown	8450	5548	5.6	2902	5.7	33,511	21,488	5.9	12,023	5.8
Spanish survey										
No	135,877	90,226	90.7	45,651	89.0	524,663	336,860	92.3	187,803	91.0
Yes	976	652	0.7	324	0.6	8565	5488	1.5	3077	1.5
Unknown	13,897	8584	8.6	5313	10.4	38,090	22,651	6.2	15,439	7.5
Proxy status										
Proxy Answered	5799	3410	3.4	2389	4.7	23,007	13,059	3.6	9948	4.8
Proxy Assistance	11,840	7037	7.1	4803	9.4	50,903	29,181	8.0	21,722	10.5
No Proxy	133,111	89,015	89.5	44,096	86.0	497,408	322,759	88.4	174,649	84.6
General health status										
Excellent	9548	6589	6.6	2959	5.8	46,963	31,776	8.7	15,187	7.4
Very Good	34,337	23,012	23.1	11,325	22.1	139,561	92,355	25.3	47,206	22.9
Good	54,986	37,170	37.4	17,816	34.7	196,252	129,325	35.4	66,927	32.4
Fair	36,588	23,648	23.8	12,940	25.2	129,440	79,313	21.7	50,127	24.3
Poor	10,207	5890	5.9	4317	8.4	38,168	19,590	5.4	18,578	9.0
Unknown	5084	3153	3.2	1931	3.8	20,934	12,640	3.5	8294	4.0

Among individuals diagnosed with more aggressive cancers, such as pancreatic cancer, the majority of surveys occurred prior to their cancer diagnosis, likely due to the short-term survival associated with these cancers. With more than 1000 cases of pancreatic cancer among individuals with MA insurance, researchers would be able to examine questions that have implications for end-of-life care and make comparisons to those with FFS coverage. Similarly, given the late stage at diagnosis, most of the lung cancer cases occur during the earlier time points in the cancer care trajectory, with sizable samples enabling comparisons by insurance type.

Additional information about SEER-CAHPS respondents is available in the Appendix tables, including data on response rates, number of respondents by SEER region, and stage information among cancer survivors by MA and FFS insurance status. Notably for respondents with the four most common cancers (i.e., breast, colorectal, lung, and prostate), localized stage was the most common, and the relative distribution of stages was similar across insurance types (Appendix Table 9).

DISCUSSION

Patient-centered care is an important component of high quality care delivered to individuals with cancer. However, limited information exists regarding patient experiences with cancer care, such as access to needed services and the quality of patient–provider communication.[24] The SEER-CAHPS data set provides an important opportunity to increase understanding of the care delivered to older cancer patients in the U.S. over multiple years.

Table 3. Number of SEER-CAHPS Respondents by First Cancer Site and Date of Diagnosis: Managed Care

First cancer	Total number of SEER linked patients	First survey before month of first cancer diagnosis		First survey within 2 years of first cancer diagnosis		First survey within 3–5 years of first cancer diagnosis		First survey within 6–10 years of first cancer diagnosis		First survey within 11+ years of first cancer diagnosis	
		N	*%*	*N*	*%*	*N*	*%*	*N*	*%*	*N*	*%*
Prostate	21,995	5023	22.8	3652	16.6	4246	19.3	5712	26.0	3362	15.3
Breast	20,030	3911	19.5	2738	13.7	2990	14.9	4658	23.3	5733	28.6
Colorectal	11,855	3599	30.4	1745	14.7	1652	13.9	2324	19.6	2535	21.4
Lung and Bronchial	7320	4767	65.1	1072	14.6	575	7.9	500	6.8	406	5.5
Ovary	1166	399	34.2	154	13.2	129	11.1	168	14.4	316	27.1
Uterine Corpus	3632	560	15.4	383	10.5	472	13.0	767	21.1	1450	39.9
Uterine Cervix	1500	61	4.1	37	2.5	81	5.4	210	14.0	1111	74.1
Bladder	5107	1572	30.8	787	15.4	754	14.8	966	18.9	1028	20.1
Melanoma	5206	1319	25.3	752	14.4	905	17.4	1040	20.0	1190	22.9
Head and Neck	4514	1453	32.2	592	13.1	636	14.1	750	16.6	1083	24.0
Kidney and Renal Pelvis	2068	726	35.1	312	15.1	312	15.1	352	17.0	366	17.7
Non-Hodgkin Lymphomas	3072	1193	38.8	485	15.8	449	14.6	501	16.3	444	14.5
Leukemia	1592	775	48.7	231	14.5	192	12.1	221	13.9	173	10.9
Stomach	982	505	51.4	171	17.4	78	7.9	105	10.7	123	12.5
Esophagus	478	321	67.2	63	13.2	50	10.5	28	5.9	16	3.3
Pancreas	1094	937	85.6	92	8.4	30	2.7	16	1.5	19	1.7
Liver and Intrahepatic Bile Duct	494	388	78.5	60	12.1	28	5.7	15	3.0	3	0.6
Simultaneous cancers*	1378	584	42.4	198	14.4	173	12.6	227	16.5	196	14.2
Other	5979	2928	49.0	821	13.7	677	11.3	677	11.3	876	14.7

* Time points for simultaneous cancers refer to the first cancer diagnosis

Pairing CAHPS surveys with claims and SEER data makes it possible to stratify patients beyond what is possible with the survey data, the claims information, or SEER data alone. Cancer patients have complex health care needs and extensive interaction with the health care system, including diagnostic services, treatment, post-treatment follow-up, and end-of-life care. Therefore, quality of care is a central aspect of their experiences in navigating cancer care and making important medical decisions. While researchers have begun to explore patient experiences, more studies are needed to provide comparative information about the care experiences of cancer patients and their non-cancer counterparts, many of whom may be living with other chronic conditions. SEER-CAHPS linked data will allow investigators to directly compare large groups of these patients by assessing their care across different points in the cancer care continuum.

Additionally, researchers will be able to compare patient experiences by type of cancer or treatment modality (e.g.,

Table 4. Number of SEER-CAHPS Respondents by First Cancer Site and Date of Diagnosis: Fee-for-Service

First cancer	Total number of SEER linked patients	First survey before month of first cancer diagnosis		First survey within 2 years of first cancer diagnosis		First survey within 3–5 years of first cancer diagnosis		First survey within 6–10 years of first cancer diagnosis		First survey within 11+ years of first cancer diagnosis	
		N	*%*	*N*	*%*	*N*	*%*	*N*	*%*	*N*	*%*
Prostate	11,341	1624	14.3	1728	15.2	2348	20.7	3252	28.7	2389	21.1
Breast	10,950	1210	11.1	1240	11.3	1848	16.9	2725	24.9	3927	35.9
Colorectal	5784	995	17.2	868	15.0	1010	17.5	1303	22.5	1608	27.8
Lung and Bronchial	3137	1537	49.0	573	18.3	392	12.5	356	11.3	279	8.9
Ovary	631	127	20.1	79	12.5	95	15.1	125	19.8	205	32.5
Uterine Corpus	2164	220	10.2	208	9.6	269	12.4	451	20.8	1016	47.0
Uterine Cervix	848	15	1.8	19	2.2	35	4.1	91	10.7	688	81.1
Bladder	2584	508	19.7	399	15.4	439	17.0	563	21.8	675	26.1
Melanoma	2945	472	16.0	409	13.9	535	18.2	673	22.9	856	29.1
Head and Neck	2525	483	19.1	344	13.6	449	17.8	497	19.7	752	29.8
Kidney and Renal Pelvis	1121	265	23.6	179	16.0	197	17.6	236	21.1	244	21.8
Non-Hodgkin Lymphomas	1608	354	22.0	281	17.5	323	20.1	341	21.2	309	19.2
Leukemia	881	262	29.7	148	16.8	147	16.7	172	19.5	152	17.3
Stomach	416	155	37.3	62	14.9	60	14.4	73	17.5	66	15.9
Esophagus	188	97	51.6	35	18.6	18	9.6	24	12.8	14	7.4
Pancreas	385	281	73.0	53	13.8	19	4.9	16	4.2	16	4.2
Liver and Intrahepatic Bile Duct	167	100	59.9	25	15.0	25	15.0	11	6.6	6	3.6
Simultaneous cancers*	654	162	24.8	115	17.6	108	16.5	138	21.1	131	20.0
Other	2959	919	31.1	473	16.0	446	15.1	483	16.3	638	21.6

* Time points for simultaneous cancers refer to the first cancer diagnosis

cancer stage, surgical and/or radiation treatment). This linkage will allow them to explore issues by time in the disease's course; for example, is a more recently diagnosed patient likely to report better or worse experiences with health care than a long-term survivor? Researchers will also be able to link patient experiences to outcomes, such as mortality or survival, and determine if experiences and outcomes vary by demographic characteristics.

Furthermore, this linkage enables comparisons of different models of healthcare coverage, since Medicare beneficiaries can enroll in either MA or FFS plans. Research comparing experiences of care by coverage type may provide valuable insights to policymakers in the era of healthcare reform and help Medicare beneficiaries make informed decisions about their care.

Researchers can also assess cancer patients in certain phases of their disease trajectory or in specific care settings (e.g., hospice care). For instance, the SEER-CAHPS data can help to better understand patients' perceptions of care at the end of life, which is an area of growing interest.[25] Experiences can be compared between individuals in skilled nursing facilities and other patients, as well as between patients undergoing more and less aggressive treatment. Moreover, the experiences of cancer patients can be compared to experiences of patients who ultimately die of causes other than cancer, and this may help address gaps in the existing literature.

Finally, large enough sample sizes exist within subgroups to compare patients in several different categories (e.g., stage, cancer type, racial/ethnic group). Additional cancer cases will also become available, with future data linkages enabling further comparisons. For those with FFS coverage, the data include a 10-year trajectory of claims data that provides a more informed overall picture of the beneficiary. In assessing trends in patient experiences over time, researchers can also explore how these are influenced by changes in Medicare, especially those changes that have the most influence on patients' experiences with care.

Although these data can provide powerful new insights into the health care experiences of Medicare beneficiaries, some limitations exist. While claims data are relatively complete for FFS beneficiaries, no claims data are available for MA beneficiaries. This gap in claims information may limit sample sizes for some analyses and precludes analyses that rely on claims to compare FFS and MA. Furthermore, while we have a large sample of cancer survivors representing several different cancers in the SEER-CAHPS data set, analyses limited to certain specific cancer types and stages might not be feasible.

Additionally, the data included in the SEER database cover 28 % of the U.S. population and are only available for specific regions. Since there may be differences in demographics and care received in unrepresented areas, caution must be exercised when making inferences from this sample to the entire Medicare population.

CAHPS surveys have also changed over the years. As a result, researchers must contend with a diversity of survey types, not only within a given year, but also across different years. In analyzing CAHPS survey data that span more than a decade, some challenges may exist related to changes over time. However, there are survey items, such as the global ratings of care and composite scores of patient experiences, that are consistently available.

In conclusion, the SEER-CAHPS linkage provides opportunities to explore many research areas that existing data sets cannot address. SEER-CAHPS is a unique and comprehensive source of information about Medicare beneficiaries that includes patients' experience of care (from CAHPS), their diagnoses and treatment modalities (from SEER), and their Medicare claims activity (from CMS). These data can provide important information about the quality, cost, and utilization of health care among beneficiaries, and contribute significantly to evaluations of Medicare policies. Researchers can also conduct analyses examining patient experiences among individuals with and without cancer, many of whom may be living with other chronic conditions, such as diabetes or heart disease. In summary, this data set has the potential to inform many research areas, address gaps in the existing literature, and assist clinicians and policymakers to improve the quality of care for all Medicare beneficiaries, particularly those diagnosed with cancer.

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APPENDIX

Table 5. Response Rates

Distribution of surveys

Cohort	Number of surveys distributed	Number of surveys completed	Response rate* (Percent)	Number of surveys linked to SEER	Number of surveys not linked to SEER but taken in a SEER region	Number of surveys not linked to SEER and not taken in a SEER region
1998	119,267	89,713	75.2	7283	18,475	63,955
1999	180,564	138,216	76.5	10,034	27,129	101,053
2000	202,775	165,871	81.8	10,503	29,240	126,128
2001	379,049	282,711	74.6	18,267	52,144	212,300
2002	357,320	270,773	75.8	16,774	50,716	203,283
2003	350,175	267,532	76.4	14,775	47,549	205,208
2004	344,022	256,507	74.6	14,531	48,472	193,504
2005	340,522	249,594	73.3	13,239	47,464	188,891
2006	153,966	97,845	63.5	5049	19,546	73,250
2007	685,934	334,513	48.8	12,734	57,268	264,511
2008	672,146	407,287	60.6	15,003	75,100	317,184
2009	672,919	415,175	61.7	14,947	80,362	319,866
2010	682,836	407,924	59.7	13,240	76,766	317,918
Total	5,141,495	3,383,661	65.8	166,379	630,231	2,587,051

Note: Average annual CAHPS response rate is 71 %. The number of surveys do not match the number of respondents in Table 6, since respondents could answer more than one survey

Table 6. Demographic Characteristics of CAHPS Respondents by Cancer Status and Insurance Type: 1998–2010

Demographic characteristics	Cancer (*n*=150,750)					Non-cancer (*n*=571,318)				
	Total	MA		FFS		Total	MA		FFS	
		N	%	*N*	%		*N*	%	*N*	%
SEER region										
San Francisco	9681	7911	8.0	1770	3.5	33,018	26,193	7.2	6825	3.3
Connecticut	8591	5384	5.4	3207	6.3	29,474	17,904	4.9	11,570	5.6
Detroit	6809	3599	3.6	3210	6.3	23,673	11,755	3.2	11,918	5.8
Hawaii	4890	3275	3.3	1615	3.1	20,010	13,026	3.6	6984	3.4
Iowa	6574	2609	2.6	3965	7.7	25,338	10,108	2.8	15,230	7.4
New Mexico	5718	3782	3.8	1936	3.8	25,238	15,590	4.3	9648	4.7
Seattle	11,400	8245	8.3	3155	6.2	36,440	25,379	7.0	11,061	5.4
Utah	3886	1648	1.7	2238	4.4	17,209	8445	2.3	8764	4.2
Atlanta	3977	2623	2.6	1354	2.6	18,195	12,164	3.3	6031	2.9
San Jose	3326	2349	2.4	977	1.9	12,606	8085	2.2	4521	2.2
Los Angeles	10,429	8237	8.3	2192	4.3	47,199	36,596	10.0	10,603	5.1
Rural Georgia	147	17	0.0	130	0.3	878	191	0.1	687	0.3
Greater California	36,638	28,572	28.7	8066	15.7	149,199	111,940	30.7	37,259	18.1
Kentucky	5314	2148	2.2	3166	6.2	32,239	12,700	3.5	19,539	9.5
Louisiana	7380	4429	4.5	2951	5.8	40,550	23,033	6.3	17,517	8.5
New Jersey	16,971	9243	9.3	7728	15.1	60,052	31,890	8.7	28,162	13.6
Unknown	30	18	0.0	12	0.0					
Non-SEER	8989	5373	5.4	3616	7.1					

Table 7. Number of SEER-CAHPS Respondents with Treatment for Common Cancers: MA, by Stage and Treatment: MA

First cancer	Total number	First survey within 2 years of first cancer diagnosis		First survey within 3–5 years of first cancer diagnosis		First survey within 6–10 years of first cancer diagnosis		First survey within 11+ years of first cancer diagnosis	
		N	%	*N*	%	*N*	%	*N*	%
Prostate									
Had Surgery	7461	1079.0	29.5	1539	36.2	2686	47.0	2157	64.2
Had Radiation	6398	1574	43.1	1720	40.5	2132	37.3	972	28.9
Had Both	759	108	3.0	125	2.9	267	4.7	259	7.7
Breast									
Had Surgery	15,418	2643	96.5	2919	97.6	4502	96.7	5354	93.4
Had Radiation	6218	1177	43.0	1361	45.5	1997	42.9	1683	29.4
Had Both	6178	1167	42.6	1353	45.3	1988	42.7	1670	29.1
Colorectal									
Had Surgery	7782	1667	95.5	1595	96.5	2220	95.5	2300	90.7
Had Radiation	668	161	9.2	142	8.6	193	8.3	172	6.8
Had Both	617	144	8.3	128	7.7	178	7.7	167	6.6
Lung and Bronchial									
Had Surgery	1650	466	43.5	427	74.3	408	81.6	349	86.0
Had Radiation	659	372	34.7	134	23.3	96	19.2	57	14.0
Had Both	220	75	7.0	53	9.2	43	8.6	49	12.1

Table 8. Number of SEER-CAHPS Respondents with Treatment for Common Cancers: FFS, by Stage and Treatment: FFS

First cancer	Total number	First survey within 2 years of first cancer diagnosis		First survey within 3–5 years of first cancer diagnosis		First survey within 6–10 years of first cancer diagnosis		First survey within 11+ years of first cancer diagnosis	
		N	%	*N*	%	*N*	%	*N*	%
Prostate									
Had Surgery	4392	534	30.9	816	34.8	1493	45.9	1549	64.8
Had Radiation	3635	750	43.4	1017	43.3	1224	37.6	644	27.0
Had Both	458	56	3.2	64	2.7	151	4.6	187	7.8
Breast									
Had Surgery	9092	1193	96.2	1795	97.1	2621	96.2	3483	88.7
Had Radiation	3608	532	42.9	851	46.0	1159	42.5	1066	27.1
Had Both	3568	526	42.4	840	45.5	1144	42.0	1058	26.9
Colon									
Had Surgery	4430	814	93.8	971	96.1	1235	94.8	1410	87.7
Had Radiation	450	87	10.0	114	11.3	122	9.4	127	7.9
Had Both	414	73	8.4	104	10.3	115	8.8	122	7.6
Lung and Bronchial									
Had Surgery	1008	245	42.8	270	68.9	274	77.0	219	78.5
Had Radiation	433	202	35.3	109	27.8	80	22.5	42	15.1
Had Both	132	27	4.7	47	12.0	30	8.4	28	10.0

Table 9. Number of SEER-CAHPS Respondents with Stage for Common Cancers: MA and FFS, by Stage and Treatment: MA and FFS

First cancer	Total number	First survey within 2 years of first cancer diagnosis		First survey within 3–5 years of first cancer diagnosis		First survey within 6–10 years of first cancer diagnosis		First survey within 11+ years of first cancer diagnosis	
		N	*%*	*N*	*%*	*N*	*%*	*N*	*%*
MA									
Prostate									
In situ	2	0	0.0	1	0.0	1	0.0	0	0.0
Distant	234	130	3.6	66	1.6	30	0.5	8	0.2
Localized/regional	10,468	3162.0	86.6	3313	78.0	3021	52.9	972	28.9
Unstaged/missing	6268	360	9.9	866	20.4	2660	46.6	2382	70.9
Breast									
In situ	2236	451	16.5	522	17.5	639	13.7	624	10.9
Localized	8159	1556	56.8	1682	56.3	2324	49.9	2597	45.3
Regional	2569	506	18.5	515	17.2	710	15.2	838	14.6
Distant	166	66	2.4	31	1.0	43	0.9	26	0.5
Unstaged/missing	2989	159	5.8	240	8.0	942	20.2	1648	28.7
Colorectal									
In situ	557	109	6.2	108	6.5	163	7.0	177	7.0
Localized	3435	790	45.3	766	46.4	952	41.0	927	36.6
Regional	2328	596	34.2	550	33.3	588	25.3	594	23.4
Distant	190	83	4.8	47	2.8	29	1.2	31	1.2
Unstaged/missing	1746	167	9.6	181	11.0	592	25.5	806	31.8
Lung and Bronchial									
In situ	4	1	0.1	1	0.2	1	0.2	1	0.2
Localized	915	334	31.2	265	46.1	226	45.2	90	22.2
Regional	724	343	32.0	195	33.9	131	26.2	55	13.5
Distant	313	254	23.7	36	6.3	17	3.4	6	1.5
Unstaged/missing	597	140	13.1	78	13.6	125	25.0	254	62.6
FFS									
Prostate									
In situ	3	1	0.1	1	0.0	1	0.0	0	0.0
Distant	98	34	2.0	38	1.6	20	0.6	6	0.3
Localized/regional	6327	1576	91.2	2019	86.0	2061	63.4	671	28.1
Unstaged/missing	3289	117	6.8	290	12.4	1170	36.0	1712	71.7
Breast									
In situ	1379	217	17.5	301	16.3	410	15.0	451	11.5
Localized	4746	696	56.1	1013	54.8	1425	52.3	1612	41.0
Regional	1643	237	19.1	337	18.2	442	16.2	627	16.0
Distant	97	31	2.5	33	1.8	20	0.7	13	0.3
Unstaged/missing	1875	59	4.8	164	8.9	428	15.7	1224	31.2
Colorectal									
In situ	345	71	8.2	69	6.8	94	7.2	111	6.9
Localized	2002	403	46.4	466	46.1	572	43.9	561	34.9
Regional	1373	283	32.6	317	31.4	368	28.2	405	25.2
Distant	122	60	6.9	31	3.1	20	1.5	11	0.7
Unstaged/missing	947	51	5.9	127	12.6	249	19.1	520	32.3
Lung and Bronchial									
In situ	1	0	0.0	0	0.0	1	0.3	0	0.0
Localized	593	176	30.7	175	44.6	163	45.8	79	28.3
Regional	433	187	32.6	116	29.6	97	27.2	33	11.8
Distant	235	160	27.9	49	12.5	22	6.2	4	1.4
Unstaged/missing	338	50	8.7	52	13.3	73	20.5	163	58.4