Is Self-Referral Associated with Higher Quality Care?

Craig Evan Pollack, Afshin Rastegar, Nancy L. Keating, John L. Adams, Maria Pisu, and Katherine L. Kahn

Objective. To assess the extent to which patients self-refer to cancer specialists and whether self-referral is associated with better experiences and quality of care.

Data Sources. Data from surveys and medical record abstraction collected through the Cancer Care Outcomes Research and Surveillance Consortium.

Study Design. Observational study of patients with lung and colorectal cancer diagnosed from 2003 through 2005 in five geographically defined regions and five integrated health care delivery systems.

Methods. Multivariable logistic regression models used to assess factors associated with self-referral and propensity score-weighted doubly robust models to test the association between self-referral and experiences/quality of care.

Principal Findings. Among 5,882 patients, 9.7 percent of lung cancer patients and 14.9 percent of colorectal cancer patients self-referred to at least one cancer specialist. Black patients were less likely to self-refer than white patients (odds ratio: 0.48, 95 percent confidence interval: 0.35, 0.64); patients with high incomes (vs. low) and with a college degree (vs. non-high school graduates) were significantly more likely to self-refer. Self-referral was associated with lower ratings of overall physician communication for patients with lung cancer but, conversely, higher odds of curative surgery among patients with stage I/II lung cancer.

Conclusions. A small but significant proportion of patients self-referred to their cancer specialists; rates varied by patient race and socioeconomic status. To the extent that self-referral is associated with quality, it may reinforce disparities in care.

Key Words. Self-referral, referral, lung cancer, colorectal cancer

Patients with cancer frequently receive expensive care from multiple providers, including primary care providers (PCPs), surgeons, radiation oncologists, and medical oncologists, for their diagnosis and treatment (Pham et al. 2007). Cancer patients rely upon these clinicians for high-stakes decisions that are likely to impact both survival and quality of life (Rose-Ash et al. 2012). At the same time, new models of health care delivery—including accountable care organizations and bundled payments—attempt to

improve quality, increase coordination, and control costs by altering where and how patients seek care (Fisher and Shortell 2010; Centers for Medicare & Medicaid Services 2011). While these reforms are particularly salient for cancer patients (Ferris et al. 2010; Flood, Fennell, and Devers 2012), they may be challenging to the extent that cancer patients play an active role in determining by whom their care is managed. As an important foundation for understanding current patterns of cancer care and assessing ongoing reforms, it is necessary to better understand how cancer patients select their specialists.

In general, patients may either follow the referral advice of their providers (including PCPs and specialists) or “self-refer” to a particular specialist. Self-referral, the focus of this paper, may be based on advice from friends, family, and one’s broader social network, and may be shaped by various structural factors, including the availability of providers in a geographic area and inclusion in their insurer’s provider networks (Forrest and Reid 1997; Forrest et al. 2001; Mehrotra, Forrest, and Lin 2011). Evidence suggests that a substantial proportion of breast cancer patients self-refer to surgeons (Schwartz, Woloshin, and Birkmeyer 2005; Katz et al. 2007). Patients who self-referred tended to have higher socioeconomic status and to receive care from high-volume surgeons and at designated cancer centers (Katz et al. 2007), which may lead to higher quality care.

To our knowledge, previous work has not examined self-referral among cancer patients across multiple types of cancer providers and various cancer types. Our primary goal was to examine the extent of self-referral to surgeons, medical oncologists, and radiation oncologists and to determine what sociodemographic, clinical, health insurance, and health care delivery factors are associated with self-referral among patients with incident lung and colorectal cancer. Furthermore, we examined whether self-referral is associated with better experiences and quality of care.

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METHODS

Study Design

Data were collected as part of the Cancer Care Outcomes Research and Surveillance (CanCORS) Consortium. CanCORS was designed to examine cancer care delivery in population- and health care system-based cohorts. Patients who were diagnosed with lung or colorectal cancer in 2003–2005 and living in Alabama, Iowa, Los Angeles, northern California, and North Carolina, from one of the five large health maintenance organizations who were part of the Cancer Research Network (CRN), or from one of the 15 sites in the Veterans Affairs Health Care System were eligible (Ayanian et al. 2004). This study was approved by the human subjects committees at participating institutions.

Patients and Data Collection

Adults aged 21 or older were identified through rapid case ascertainment from population-based cancer registries and pathology and cytology records. Patients, or surrogates when the patient was deceased or too ill to participate, were invited to participate. Trained interviewers surveyed patients 3–6 months following diagnosis using computer-assisted telephone interviewing. Surveys were conducted in English, Spanish, and Chinese. Of the 21,868 eligible patients, 5,150 with lung cancer and 4,911 with colorectal cancer or their proxy were interviewed (Figure 1). The American Association of Public Opinion Research response rate was 51.0 percent, and the cooperation rate among patients who could be contacted was 59.9 percent (Ayanian et al. 2010; Catalano et al. 2013).

The sample for this analysis was limited to patients and/or their surrogates who completed both the baseline and follow-up surveys and those where the medical records were abstracted ($N = 7,279$). Data for the current study were derived solely from the baseline survey (either the full or brief survey) and medical record abstraction; we do not use data from the follow-up survey in the present analyses. Patients in the Veterans Affairs system ($N = 862$) were excluded because their referral pathways were hypothesized to be significantly different from those of other patients. We excluded patients with missing data about referral for all cancer specialists (surgeons, radiation oncologist, or medical oncologist) ($N = 535$). The final sample included 5,882 patients who reported on 10,763 referral decisions to cancer specialists.

Figure 1: Cohort Definition

Definition of Self-Referral

Patients were asked a series of questions about each specialist they saw. Patients who underwent or were planning to undergo surgery were asked who referred them to their surgeon. Respondents indicated the name of the referring doctor, the name of the referring clinic, or that they self- or family-referred. Patients who were not planning surgery were asked if they ever saw a surgeon about their cancer and, if so, who referred them, with the same response options. Similar questions were asked regarding referral to physicians providing radiation and chemotherapy. For each type of cancer specialist, patients were classified according to whether they self- or family-referred (hereafter called “self-referral”) compared with other response categories. We created a summary variable that indicated whether each patient self-referred to at least one of their cancer specialists compared with those who never self-referred.

Sociodemographic and Clinical Factors

Sociodemographic characteristics from the baseline survey included patient age, sex, race/ethnicity, education, income, and language of survey adminis-

tration. Medical record data defined tumor type as small versus nonsmall cell for lung cancer and colon versus rectal cancer. Medical record data were used to assign American Joint Committee on Cancer collaborative stage and, when complete data were not available, we obtained stage data from cancer registries. Prediagnosis health status was determined from the baseline survey using five items from the Short Form 12 (SF12), categorized into quartiles (Malin et al. 2006). The number and severity of comorbidities was assessed with medical record data using the Adult Comorbidity Evaluation (ACE)-27 (Piccirillo, Costas, and Grove 2003) and patients' self-reports. Comorbidity was classified as none, mild, moderate, or severe (Kahn et al. 2010). We also created a variable to indicate whether the survey was conducted with the patient, surrogate of a living patient, or surrogate of a deceased patient.

Health Insurance and Health Care Delivery Factors

Insurance was categorized into four mutually exclusive categories defined by the survey: enrolled in both Medicare and private coverage regardless of other insurance; enrolled in Medicare but not private coverage; enrolled only in private coverage (not Medicare); and enrolled in Medicaid, other insurance plans, or uninsured. We identified whether a patient had a primary care doctor (a family doctor, a general doctor, or a specialist doctor) and include CanCORS site.

Experiences of Care

Patients or surrogates were asked 13 questions adapted from the Consumer Assessment of Healthcare Provider Systems survey (Hays et al. 1999) and other studies (Ayanian et al. 2005; Arora et al. 2009) concerning their experiences with the interpersonal aspects of care. Based upon the analysts' clinical and conceptual model of cancer patients' experiences and supported by a principal factor analysis (Ayanian et al. 2010), the items were grouped into three subscales: physician communication (five items), nursing care (two items), and coordination and responsiveness of care (six items). Responses were scaled from 0 (low quality) to 100 (high quality) (Ayanian et al. 2010).

Quality of Care Indicators

Patients or surrogates also assigned a single-item overall quality-of-cancer-care value, using a 5-point scale (excellent to poor) with responses dichotomized as excellent versus all other responses.

Additionally, we assessed the receipt of guideline-concordant care: curative surgery (pneumonectomy, lobectomy, or wedge resection) for stage I/II nonsmall cell lung cancer based on medical record abstraction, adjuvant chemotherapy for patients with stage III colon cancer, and adjuvant chemotherapy and radiation therapy for stage II/III rectal cancer (National Comprehensive Cancer Network 2014). The receipt of chemotherapy and radiation was defined by patient or surrogate report and medical record review.

Statistical Analysis

We first examined the frequency and correlates of self-referral. In bivariate analyses and multivariable logistic regression models, we examined whether patients who self-referred to at least one of their cancer specialists were significantly different from those who did not self-refer. Logistic regression models included all sociodemographic, clinical, insurance, and health care delivery-related factors, as well as dummy variables to indicate how many different cancer specialists that patient had seen (ranging from 1 to 3). After checking for collinearity using variance inflation factors (VIFs), we opted to exclude whether the patient had a PCP from our final model (VIF equaled 10.3 for lung cancer and 8.7 for CRC). Missing data were 1.1 percent for education, 6.4 percent for marital status, 19.0 percent for income, and 29.8 percent for health status prior to diagnosis; we employed multiple imputation (multivariate imputation) for patient covariates but not for referrals and outcomes (He et al. 2010). Sensitivity analyses in which we excluded variables with high missingness (income and health status prior to diagnosis) did not significantly alter our findings.

We then examined the association between self-referral and experiences and quality of care. To achieve balance on observable factors among patients who self-referred and similar patients who did not, we used doubly robust, propensity score-weighted models. Propensity scores were constructed using all sociodemographic, clinical, insurance, health care delivery-related factors, and dummy variables for the type(s) of cancer specialist the patient had seen, and vital status (indicated by whether the patient responded to the survey, the surrogate of a living patient, or the surrogate of a deceased patient). Propensity scores were calculated in *R* version 2.13.1 using *Twang* version 1.6-3.1 and generated separately by cancer type (for stratified analyses) and for each outcome; adequate balance was achieved in each instance. The propensity score was incorporated into our regression

models as an inverse probability weight where each patient who did not self-refer was given the weight $e_i/(1-e_i)$, where e is the propensity score for person i , and each patient who self-referred was given the weight of 1 (i.e., treatment on treated) (Wooldridge 2013). While all variables were used in constructing the propensity scores, high VIFs prompted the removal of several variables from the “doubly robust” portion of the models (see Figure 3 for complete list of included variables). Analyses were performed in *Stata* version 10.0 (Stata Corp., College Station, TX, USA).

RESULTS

Our sample consisted of 5,882 patients: 3,010 were diagnosed with lung cancer and 2,872 with CRC (Table 1). For both cancers, most patients were male and aged ≥ 65 . Over one-third of lung cancer patients (39.1 percent) saw a single type of cancer specialist, 43.3 percent saw two types, and the remaining 17.6 percent saw all three. Similarly, 33.4 percent of CRC patients saw a single type of cancer specialist, 45.6 percent saw two, and 21.0 percent saw all three.

Self-referral varied by the type of specialist and cancer type (Figure 2). Across both cancer types, patients were least likely to self-refer to radiation oncologists (4.7 percent for lung cancer, 5.1 percent for CRC). Patients with lung cancer were most likely to self-refer to their medical oncologist (8.8 percent) and those with CRC were most likely to self-refer to their surgeon (10.9 percent). Overall, 9.7 percent of patients with lung cancer and 14.9 percent of patients with CRC self-referred to at least one cancer provider. Between 10.9 percent and 16.1 percent did not know who referred them to each specialist type.

In bivariate analyses (presented stratified by cancer type) and multivariable analyses (in which we adjust for cancer type), black patients with either lung cancer or CRC were significantly less likely to self-refer than white patients (odds ratio [OR]: 0.48, 95 percent confidence interval [CI]: 0.35, 0.64) (Table 1). High likelihoods of self-referral were observed among patients with the highest incomes compared to the lowest (OR: 1.72, 95 percent CI: 1.18, 2.49) and college graduates compared to patients who did not graduate high school (OR: 1.53, 95 percent CI: 1.13, 2.05). Patients who saw more than one type of cancer specialist were significantly more likely to self-refer, as were patients with colon cancer compared to lung cancer (either small cell or nonsmall cell). Sur-

Table 1: Sample Characteristics, Bivariate, and Multivariable Analyses Showing Factors Associated with Self-Referral to at Least One Cancer Specialist

	Lung Cancer		CRC		Combined Multivariable Model Adjusted Odds Ratios of Self-Referral to at Least One Cancer Specialist (95% Confidence Interval)
	N	% Self-Referral to at Least One Specialist	N	% Self-Referral to at Least One Specialist	
Total patients	3,010	9.7	2,872	14.9	
Sociodemographic characteristics					
Age					
<55	362	11.6	622	14.3	1.00
55–64	730	11	612	16.7	1.16 (0.90–1.50)
65–74	1,060	10.8	741	14.8	1.15 (0.84–1.58)
75+	858	6.5**	897	14.3	1.04 (0.75–1.45)
Sex					
Male	1,616	8.9	1,505	15.6	1.00
Female	1,394	10.7	1,367	14.3	1.12 (0.94–1.33)
Race					
White	2,314	10.3	1,909	17.8	1.00
Black	289	6.6	452	9.1	0.48 (0.35–0.64)**
Other	407	8.4	511	9.6***	0.83 (0.63–1.09)
Language of survey administration					
English	2,955	9.8	2,771	15.3	1.00
Not English	55	3.6	101	5**	0.50 (0.22–1.12)
Marital status					
Married	1,143	9.7	1,095	13.6	1.00
Not married	1,867	9.7	1,777	15.8	0.90 (0.74–1.09)

Continued

Table 1: Continued

	Lung Cancer		CRC		Combined Multivariable Model Adjusted Odds Ratios of Self-Referral to at Least One Cancer Specialist (95% Confidence Interval)
	N	% Self-Referral to at Least One Specialist	N	% Self-Referral to at Least One Specialist	
Income					
<\$20,000	904	8.3	730	11.4	1.00
\$20 to <\$40,000	1,032	9.5	841	14.3	1.13 (0.88–1.45)
\$40 to <\$60,000	581	9	597	16.8	1.14 (0.80–1.62)
\$60 to <\$80,000	195	10.3	225	20.9	1.43 (0.98–2.08)
\$80 to <\$100,000	115	9.6	194	13.4	0.97 (0.62–1.52)
\$100,000+	183	19.7***	285	18.6**	1.72 (1.18–2.49)**
Education					
<High school graduate	654	7.2	555	12.1	1.00
High school graduate	1,067	9	761	14.2	1.13 (0.87–1.47)
Some college	751	9.9	502	15.3	1.23 (0.93–1.64)
College graduate	538	13.9***	1,054	16.8	1.53 (1.13–2.05)**
Clinical characteristics					
Comorbidities					
None	346	12.7	637	16	1.00
1	1,010	10.7	1,174	14.9	0.99 (0.79–1.24)
2	804	8.3	627	14.4	0.89 (0.68–1.15)
3 or more	850	8.6	434	14.3	0.97 (0.73–1.28)

Continued

Table 1: *Continued*

	<i>Lung Cancer</i>		<i>CRC</i>		<i>Combined Multivariable Model Adjusted Odds Ratios of Self-Referral to at Least One Cancer Specialist (95% Confidence Interval)</i>
	<i>N</i>	<i>% Self-Referral to at Least One Specialist</i>	<i>N</i>	<i>% Self-Referral to at Least One Specialist</i>	
Health status prior to diagnosis					
Lowest quartile	798	7.4	717	13.8	1.00
Middle low	708	10.2	687	15.6	1.15 (0.90–1.47)
Middle high	739	10.8	720	15.3	1.18 (0.87–1.59)
Highest quartile	765	10.6	748	15.1	1.06 (0.79–1.42)
Tumor stage					
1 or 2	943	8.5	1,435	14.2	1.00
3	822	11.2	849	16.7	1.06 (0.87–1.29)
4	1,175	9.6	530	14.5	1.08 (0.86–1.35)
Unknown	70	10	58	10.3	0.92 (0.50–1.69)
Cancer type					
Colon	2,641		2,149	14.8	1.00
Rectal	369		723	15.4	1.00 (0.77–1.30)
Non-small cell	2,641	9.9			0.74 (0.59–0.92)**
Small cell	369	8.4			0.57 (0.38–0.88)*
Health care factors					
Number of times referred					
1	1,176	5.1	959	9.1	1.00
2	1,303	12.2	1,310	18.2	2.28 (1.84–2.82)***
3	531	13.8***	603	17.1***	2.26 (1.74–2.93)***

Continued

Table 1: Continued

	Lung Cancer		CRC		Combined Multivariable Model Adjusted Odds Ratios of Self-Referral to at Least One Cancer Specialist (95% Confidence Interval)
	N	% Self-Referral to at Least One Specialist	N	% Self-Referral to at Least One Specialist	
Type of insurance					
Medicare and private	1,567	9.4	1,162	14.9	1.00
Medicare not private	472	9.1	508	13.6	1.01 (0.79–1.30)
Private not Medicare	830	10.8	1,066	16.1	0.92 (0.70–1.20)
Medicaid, other, none	141	8.5	136	11	0.92 (0.58–1.45)
Has a primary care provider [†]					
No	292	13	321	15.9	
Yes	2,718	9.4*	2,551	14.8	
Other factors					
Type of survey					
Patient	1,892	11.1	2,342	15.5	1.00
Surrogate of living patient	282	6.7	295	14.9	0.97 (0.72–1.31)
Surrogate of deceased patient	836	7.5**	235	9.4*	0.74 (0.57–0.98)*
Site					
Northern California	425	7.8	482	11	1.00
Alabama	472	9.5	501	19.2	2.01 (1.47–2.74)***
Los Angeles County	486	10.7	473	10.4	1.14 (0.84–1.56)
Iowa	807	11.2			1.51 (1.07–2.15)*
North Carolina			679	20.5	2.16 (1.57–2.96)***
Kaiser Permanent, CA	306	8.2	216	11.1	1.06 (0.73–1.53)
Cancer Research Network	514	9.2	494	13.2***	1.17 (0.86–1.60)

[†]Excluded from multivariable analyses due to high collinearity.
* $p < .05$, ** $p < .01$, *** $p < .001$.

Figure 2: Referral Pathway for Patients to Their Surgeon, Radiation Oncologist, and Medical Oncologist, Stratified by Lung and Colorectal Cancer

rogates of deceased patients with lung cancer reported lower odds of self-referral compared to patient reports (OR: 0.74, 95 percent CI: 0.57, 0.98). While we observed some variation across CanCORS sites, we did not see significant associations between self-referral and clinical factors, insurance-related factors, or other factors related to health care delivery.

Figure 3 presents the doubly robust associations between self-referral and experiences of care, patient (or surrogate)-reported quality, and processes of care (bivariate analyses are presented in Table S1). Patients with lung cancer who self-referred reported lower satisfaction with physician communication compared to patients who did not self-refer (Beta-coefficient: -2.92 , 95 percent CI: -5.49 , -0.35). We did not observe significant differences in other experiences of care by self-referral. Self-referral was not associated with self-reported overall quality of care. Self-referral to one's surgeon was associated with significantly higher odds of curative surgery for early-stage lung cancer (OR: 20.75, 95 percent CI: 7.46, 57.75); it was not associated with the receipt of adjuvant therapy for patients with stage III colon or stages II/III rectal cancer.

Figure 3: Adjusted Association between Self-Referral and (a) Better Experiences with the Interpersonal Aspects of Care and (b) Patient/Surrogate-Reported Experiences of Care and Quality of Care for Patients with Lung and Colorectal Cancer Using Doubly Robust Propensity Score-Weighted Models

Note: Doubly robust models adjust for propensity weights and sociodemographic, clinical, insurance, and health care delivery-related factors. Due to collinearity, the following variables were removed: from the overall quality of care, we omitted whether the patient had a PCP; for adjuvant chemotherapy for stage III colon cancer, we omitted age, insurance, education, income, marital status, PCP status, and number of different providers referred to; for adjuvant chemotherapy and radiation for rectal cancer, we omitted age, insurance, education, income, marital status, comorbidity, PCP status, number of different providers referred to, and CanCORS site; for curative surgery for early-stage lung cancer, we omitted age, comorbidity, and PCP status.

DISCUSSION

In this large, representative cohort of cancer patients, we observed that self-referral to cancer specialists occurred in nearly 10 percent of patients with lung cancer and 15 percent of patients with CRC. Patients were most likely to self-refer to medical oncologists for lung cancer and surgeons for CRC; they were least likely to refer to radiation oncologists. Patient race and socioeconomic status were significant predictors of self-referral, whereas clinical and insurance-related factors were not. Self-referral was associated with lower ratings of physician communication and higher odds of curative surgery for patients with lung cancer—though wide confidence intervals highlight the instability of the latter estimate.

The rates of self-referral are consistent with, though lower than, data from older studies of patients in point-of-service plans that reported

self-referral rates ranging from 7.5 to 20.5 percent to a general surgeon and 18.2 to 22.2 percent to hematology/oncology specialist (Forrest et al. 2001). This prior research focused on referrals from PCPs with “gatekeeper” arrangements, which may not be directly applicable to much of our cohort. In a population-based sample, Katz and colleagues found that 20.3 percent of women with breast cancer selected their surgeon on their own, whereas another 21.9 percent reported that they were referred but were also involved in the surgeon selection (Katz et al. 2007). As we demonstrated, the likelihood of self-referral varied by cancer type and by the type of specialist seen. We examined referral as a binary indicator, though patients may have engaged in shared decision making with their referring providers about whether to seek care from a particular specialist.

Lower rates of self-referral were observed among black patients and among patients with the lowest socioeconomic status as measured by household income and education. Other evidence suggests that referral patterns contribute to black patients receiving coronary surgery from lower quality surgeons (Mukamel, Weimer, and Mushlin 2006). With the observed associations of self-referral with quality in our study, the lower rates of self-referral among disadvantaged subgroups is worthy of further study to assess if they contribute to disparate outcomes.

Surprisingly, we did not observe significant variation in likelihood of self-referral by type of health insurance and we did not find lower rates of self-referral among patients recruited from health maintenance organizations (i.e., Kaiser Permanente of Northern and Southern California and the CRN). The heterogeneity of systems represented by the CRN (with regard to payment and health care delivery) may have contributed to the lack of association. Furthermore, we could not assess specific features of managed care arrangements (e.g., insurance with closed networks or gatekeeper arrangements) that may influence patterns of self-referral (Forrest and Reid 1997; Forrest et al. 2001).

While self-referral is important for a segment of patients, the majority of patients in our sample followed the recommendations of their physicians when deciding where to seek specialty care. Previous studies have shown that doctors choose specialists based on medical skill and perceived prestige of the specialist (Shortell 1973; Javalgi et al. 1993; Kinchen et al. 2004; Barnett et al. 2012). The results of the current study underscore the importance of physician recommendations and the need for a deeper understanding of what motivates these choices (Mehrotra, Forrest, and Lin 2011).

Our findings regarding the association between self-referral and experiences and quality of care warrant careful scrutiny. We found an association between self-referral and lower ratings of physician communication among patients with lung cancer, whereas findings were not significant among patients with CRC or with respect to nursing care or care coordination. It is possible that frustration with one's physician—rather than dissatisfaction with the nursing staff or coordination—may motivate some patients to self-refer. In prior work, relationship problems with one's PCPs have been associated with higher rates of self-referral in point-of-service health plans (Forrest et al. 2001). Self-referral was associated with a higher odds of receiving curative surgery for early-stage lung cancer. It is plausible that some patients self-refer who may not have otherwise seen a surgeon. In this scenario, patients may be more effectively navigating the health care system to receive evidence-based care. Alternatively, patients may be seeking a second opinion about whether to undergo surgery or trying to find the best specialist once they have decided to undergo lung cancer surgery.

Despite the richness of the demographic, clinical, and structural data in CanCORS, our analysis was limited by the lack of detail about some aspects of the nature, quality, and context of the referral. As noted below, these are important features to disentangle in future research. Our research has additional limitations. First, we are unable to distinguish whether patients were describing their experiences of care prior to or following their self-referral, which restricts our ability to determine causality. Second, because we were unable to distinguish the timing of the referrals, we opted not to examine the characteristics of patients who self-referred to multiple specialists. These individuals may have different characteristics and outcomes compared to patients who self-refer to a single type of specialist. Third, though we adjust for CanCORS site and measures of insurance, we were unable to assess the availability of cancer specialists in given areas and lacked important detail on restricted provider networks, which may have impeded a patient's ability to self-refer. Lastly, survey research is subject to recall and nonresponse biases; CanCORS used rapid case ascertainment and it has been shown to be demographically representative relative to patients from the Surveillance, Epidemiology, and End Results population (Catalano et al. 2013).

Nevertheless, this analysis has provided important data from a population-based sample about the clinical epidemiology of self-referrals for patients with two incident cancers, predictors of self-referral and outcomes. These

analyses allowed us to recognize a framework of data elements that should be considered in future analysis of self-referral. As networked health care delivery systems become increasingly prevalent, data for addressing these currently unanswered questions will become more available and allow us to answer these critical questions. In particular, future research should assess the information sources that patients use when deciding where to seek care (e.g., information from family, friends, or other members of their social network; use of online resources) and clearly delineate the reasons why patients self-refer. Patients may have opted to self-refer due to dissatisfaction with a specialist, because their providers had not referred them to a particular type of specialist, to receive a second opinion, to verify or challenge their existing diagnosis and/or treatment options, or to receive a treatment from a particular provider (e.g., after a patient has already decided on surgery). Patients may self-refer to different levels of care, including particular doctors, clinics, or cancer clinics, which may impact experiences and quality. Additionally, investigating the timing of self-referrals may be important. A patient who self-refers to his/her initial cancer specialist may see different providers (due to subsequent physician-referral) compared with patients who self-refer later in their course of diagnosis and treatment. It will be important to better delineate structural features of health insurance and care delivery as researchers seek to understand the drivers and impacts of patients who make their own decisions about where to seek care. The emergence of accountable care and the potential for restrictive networks may also change the extent to which patients are able to self-refer for specialty care (Shortell et al. 2014). Each of these aspects may impact whether self-referral is associated with experiences and quality of care.

From a policy perspective, insurers and health care systems may expect that a small but significant proportion of patients with lung and colorectal cancer will elect to self-refer to cancer specialists. Patients who self-refer may create challenges as reforms seek to manage patient care. With self-referral correlating with socioeconomic status and patient race, it is necessary to further examine whether and in what circumstances differences in self-referral may contribute to disparate outcomes.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of this article:

Appendix SA1: Author Matrix.

Table S1. Bivariate Analyses of the Association between Self-Referral and Outcomes.