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Current Practices for Screening and Addressing Financial Hardship within the National Cancer Institute's Community Oncology Research Program

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Abstract

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Background: Cancer-related financial hardship is associated with poor care outcomes and reduced quality-of-life for patients and families. Scalable intervention development to address financial hardship requires knowledge of current screening practices and services within community cancer care.

Materials and Methods: The National Cancer Institute's Community Oncology Research Program (NCORP) 2017 Landscape Assessment survey assessed financial screening and financial navigation practices within U.S. community oncology practices. Logistic models evaluated associations between financial hardship screening and availability of a cancer-specific financial navigator and practice group characteristics (e.g., safety-net designation, critical access hospital, proportion of racial and ethnic minority patients served).

Results: Of 221 participating NCORP practice groups, 72% reported a financial screening process and 50% had a cancer-specific financial navigator. Practice groups with more than 10% of new cancer patients enrolled in Medicaid ($_{adj}OR = 2.81$, p = .02) and with less than 30% racial/ ethnic minority cancer patient composition ($_{adj}OR = 3.91$, p < .01) were more likely to screen for financial concerns. Practice groups with less than 30% racial/ethnic minority cancer patient composition ($_{adj}OR = 2.37$, p < .01) were more likely to have a dedicated financial navigator or counselor for cancer patients.

Conclusions: Most NCORP practice groups screen for financial concerns and half have a cancer-specific financial navigator. Practices serving more racial or ethnic minority patients are less likely to screen and have a designated financial navigator.

Impact: The effectiveness of financial screening and navigation for mitigating financial hardship could be tested within NCORP, along with specific interventions to address cancer care inequities.

Introduction

Financial hardship, a term describing the negative psychological, behavioral, and material costs associated with the financial implications of cancer and its treatment (1), affects 40-50% of cancer survivors (2). Survivors with inadequate insurance coverage and limited socioeconomic status, financial resources, and health literacy are at elevated risk for financial hardship (2,3). Consequences of financial hardship include increased depression and anxiety and reduced quality of life, treatment adherence, and survival (2).

Although multilevel intervention strategies are needed to comprehensively address financial hardship (e.g., policy changes to reduce drug costs and increase price transparency, insurance access) (3), at the patient level, addressing financial hardship requires cancer care facilities identify patients who are most at risk and provide requisite resources to mitigate risk (3,4). Unfortunately, whether and how cancer care facilities screen for risk factors and provide financial services is not well defined. A recent survey of 17 National Comprehensive Cancer Network (NCCN) centers found over 75% screen for financial hardship; however, barriers to effectively managing financial hardship such as inadequate staffing were also noted, especially among centers serving fewer than 10,000 patients a year (5). These findings, while a helpful benchmark for monitoring progress in addressing financial hardship in NCCN centers, do not address the prevalence of practices to detect and mitigate financial hardship in the community oncology setting where most cancer care

occurs (6,7). Patients seeking care in community cancer care facilities may be at heightened risk for financial hardship due to both practice and patient-level factors. On a practice level, the size and resources available in community cancer care facilities may vary more compared to academic medical centers, which could limit services to address financial hardship. Further, community cancer facilities often serve rural and under- or uninsured patients, both of which are risk factors for financial hardship (8-10). These combined risk factors highlight the critical need to understand existing practices and resources that can be leveraged for interventions to address financial hardship in community cancer care.

The aim of this research is to describe existing screening and service practices to address financial hardship among survivors treated within the National Cancer Institute's Community Oncology Research Program (NCORP), a network of community oncology practices across the U.S. We aimed to describe the prevalence of financial screening, sources of financial navigation services, and availability of cancer-specific financial navigators within NCORP. To identify priority areas for future research and resource development, this study also examines practice group characteristics associated with offering financial screening and a cancer-specific financial navigator. We hypothesized most practice groups would report some type of financial services, but, given the current lack of guidelines on screening (11), few would screen for financial concerns.

Materials and Methods

Study Design and Participants

The data reported in this study are from the 2017 NCORP Cancer Care Delivery Research Landscape Assessment, previously described in detail (12,13). Briefly, the Landscape Assessment surveyed NCORP community oncology clinic administrators and research staff on existing practice characteristics and capacity for cancer care delivery research (14). Practices are administratively organized within 46 NCORP Community Sites, which are consortia of researchers, public hospitals, physician practices, and academic medical centers for the purposes of administering the NCI NCORP grant and coordinating clinical trials operations. The distinct hospitals and clinics within this network are referred to as components/subcomponents. Respondents could self-identify as a practice group, multiple clinics and/or hospitals sharing providers, patients, and infrastructure tethered to a common electronic health record; in this situation, a representative completed one survey on behalf of the practice group. Recruitment emails and at least two reminders were sent to administrators at each NCORP site, who then distributed communications to components/ subcomponents. Multiple webinars were conducted to educate the NCORP network about this effort.

Landscape survey items were selected from questions submitted by NCORP Research Bases, Community and Minority/Underserved Community Sites, and affiliated investigators after review for clarity, applicability to community oncology, scientific priority, and likelihood of informing NCORP research proposals. This study was reviewed and identified as exempt by the Wake Forest Health Sciences Institutional Review Board.

Measures

Financial screening practices were assessed with two items: "Does your component/ subcomponent have a financial screening process for oncology patients (i.e., to identify patients with financial distress or at high risk for developing financial distress)" (yes/no; Primary financial screening outcome); "If yes, how is financial screening done (yes/no for each – questions in the electronic health record, patient intake form, vitals or other form completed by nurse or nurse assistant, other system not listed, please specify)."

Financial Navigation Services.—We consulted with NCORP practice groups during survey development to inform strategies for assessing financial navigation. Because practice groups did not view financial navigation as a one-time event or limited to one provider type, the survey assessed multiple potential navigation sources.

The survey provided the following description of financial navigation: "*Financial navigation refers to processes by which patients are aided in maximizing their financial assistance after a cancer diagnosis to avoid adverse financial consequences and hardship associated with cancer treatment (e.g., education about and assistance with accessing appropriate financial programs and services*). "The survey then asked practice groups: *Who provides the majority of financial navigation services to patients at your component/subcomponent?*" Yes/no response options were available for six items (listed in survey order of appearance): *1*) *Dedicated financial navigator or counselor who serves cancer patients* (Primary financial navigation outcome); *2*) a general financial navigator or counselor that is not dedicated to cancer patients (*e.g., an individual that serves the entire hospital or select departments*); *3*) social worker; *4*) billing staff; *5*) referred to outside counseling or case management (if yes, American Cancer Society, other patient advocacy group, other financial counseling service); *6*) none of the above. Respondents could select "yes" for more than one.

Practice group characteristics (i.e., critical access hospital, number of new cancer cases seen a year, sociodemographic composition of patient population) were selected based on existing literature (3,5,12). Whether a practice group contained a hospital that was designated by the Centers for Medicare and Medicaid as a critical access hospital (i.e., located in a rural or underserved area with fewer than 25 inpatient beds (15) was used as a marker for rural location.

Statistical Analyses

Primary outcomes were the proportion of NCORP practice groups that (1) screen for financial concerns; and (2) provide financial navigation services with a dedicated financial navigator or counselor who serves cancer patients. Secondary outcomes included describing the methods sites used to screen for financial concerns, and the various types of financial navigation services offered. Outcomes were assessed for differences by site practice characteristics (e.g., regional area where site is located, total annual number of new adult cancer cases (<1000 or 1000+), self-identification of outpatient or hospital oncology clinic, free-standing or Private group, offering inpatient services, Safety-Net Hospital or Critical Access Hospital (16) and patient characteristics within NCORP practice groups (e.g., proportion of new cancer patients on Medicaid with/without Medicare, proportion of new

cancer patients uninsured and/or charity care, racial and ethnic minority representation). A 10% comparator cutoff was selected for insurance payer mix (i.e., uninsured/Charity care) based on prior research (5,12). A 30% comparator cutoff was selected for practice group racial and ethnic minority patient composition to align with the NCORP definition of a minority/underserved practice.

Univariate differences were assessed by Fisher's exact tests with frequency/percent and corresponding p-values. Logistic models were constructed for financial screening and dedicated cancer financial navigation services with the consideration of site and patient characteristics listed above utilizing stepwise model selection with entry criteria of alpha=0.15 with adjusted odds ratios and 95% confidence intervals. Fisher's exact tests were also used to examine whether NCORP practice groups that screened for financial concerns were more likely to have a financial navigator. All analyses were conducted in SAS (v.9.4, Cary, NC) with a two-sided alpha of 0.05 as the criteria for statistical significance.

Results

NCORP Practice Group Characteristics

Of the 943 NCORP discrete practice locations at the time of survey, 504 (54%) responded to the survey alone or part of a practice group, representing a total of 227 practice groups. Table 1 displays the practice group characteristics. Over half (56%) of practice groups saw at least 1000 new adult (ages 18+) cancer cases a year. 50% of practice groups were located in the Midwest; only 6% were in the Northeast. Most (83%) practice groups offered inpatient services. Only 21% were designated as critical access and 25% identified as a safety-net hospital. 44% reported over 10% of their new cancer patients were either Medicaid or dual Medicaid/Medicare enrolled, and 26% reported at least 30% of their new cancer patients were racial/ethnic minorities.

Financial Screening Practices (Table 2)

72% (n = 159) of practice groups reported a financial screening process for cancer patients. Table 2 shows the most common financial screening process was a patient intake form (68%; n = 108), followed by 47% (n=73) reporting an "other" response using free text (e.g., "distress thermometer", or "lack of insurance triggers referral to social work for screening"). Respondents less commonly reported screening through the electronic health record (EHR; 28%), or as part of vitals or a form completed by a nurse or nurse assistant (29%).

Sources of Financial Navigation Services

As shown in Table 2, 50% (n = 110) of practice groups reported a financial navigator or counselor designated to cancer patients as a source of financial navigation.

Other sources of financial navigation included social workers (67%; n = 147), outside agency referrals (52%; n = 114; most commonly the American Cancer Society), billing staff (49%; n = 107), and a general financial navigator (36%; n = 79).

Correlates of Financial Screening and Dedicated Financial Navigator for Cancer Patients

Table 3 displays univariate associations between practice group characteristics and whether a practice group screened for patient financial concerns and had a financial navigator dedicated to seeing cancer patients.

Table 4 shows adjusted odds ratios of practice group characteristics associated with: 1) financial screening and 2) offering a financial navigator dedicated to cancer patients. Practice groups with more than 10% of new cancer patients enrolled in Medicaid with/ without Medicare ($_{adj}OR = 2.81$, p = .02) and with less than 30% racial/ethnic minority patient composition ($_{adj}OR = 3.91$, p < .01) were more likely to screen for financial concerns. U.S. region was also related to financial screening (p = .04) and was driven by the South being more likely to screen than the Northeast after adjusting for post-hoc comparisons ($_{adj}OR = 7.06$, p = .03). Practice groups with less than 30% racial/ethnic minority patient composition ($_{adj}OR = 2.37$, p < .01) were more likely to have a dedicated financial navigator or counselor for cancer patients. No other variables were retained or significant in the model.

Association between having a Cancer-Specific Financial Navigator and Screening for Financial Concerns.

A higher proportion of NCORP practice groups that had a cancer-specific financial navigator reported a financial screening process (84.6% of sites with a cancer-specific financial navigator screened for financial concerns vs. 58.7% of NCORP practice groups without a cancer financial navigator, p < .001).

Discussion

Routine identification and management of cancer patients' financial concerns is essential as cancer care costs rise. This study described capacity to address financial concerns in community cancer care facilities within a national community cancer research network. Most NCORP community oncology practice groups had a financial screening process. Practice groups reported multiple potential sources of financial navigation services, but cancer-specific financial navigators were available at only half of the practice groups. Critically, fewer NCORP practice groups serving a higher proportion of racial and ethnic minority patients screened for financial concerns and had a designated financial navigator for cancer patients. Our results highlight several opportunities to improve identification of cancer patients who may be vulnerable to financial hardship and to increase services to address financial hardship in community cancer care.

The majority of NCORP practice groups in this study (72%) reported a financial screening process. This was higher than hypothesized and very similar to the financial screening rate found in a recent survey of 17 NCCN centers (5). However, screening methods varied and the most common methods (e.g., intake forms) may suggest a focus on insurance coverage. While critical for identifying at-risk patients, screening that relies solely on insurance coverage will likely miss other important components of financial hardship such as financial sacrifices made to cover care costs, depletion of savings, patient and caregiver employment concerns, and distress. Even if screening at intake focuses on more than insurance coverage,

reliance on intake would be problematic because patients will not have received cancer healthcare bills and thus may not know their level of need or present with financial distress. Practice groups that use the NCCN distress thermometer problem checklist as part of required distress screening may be able to detect financial distress throughout cancer care. Whether and how well the NCCN distress thermometer identifies other components of financial hardship is an important question for future research. The survey of NCCN centers similarly identified the distress thermometer as one of several screening tools used (5). The diversity of screening tools used in NCORP practice groups and NCCN centers reflects the lack of an agreed-upon screening mechanism (11) and underscores the need to evaluate the utility of existing methods and potential for new measures (e.g., FACIT-COST(17)) in clinical practice.

Nearly all NCORP practice groups reported at least one source of financial navigation, defined in this study as processes by which financial assistance is maximized for patients. Practice groups reported social workers, financial navigators, hospital billing staff, and referrals to the American Cancer Society as sources of financial navigation. The diversity of sources of financial navigation in NCORP practice groups is consistent with findings from NCCN centers (5). Although the availability of multiple potential sources of financial navigation presents opportunities for points of intervention, availability alone is unlikely to translate into effective interventions. Patient financial resources are often fragmented and care pathways ill-defined (18,19).

Although the Landscape survey allowed practice groups to indicate multiple sources of financial navigation, our primary financial navigation outcome was whether practice groups had a financial navigator or counselor who was dedicated specifically to serving cancer patients. This outcome was selected because it suggested a delineated role and potentially a higher level of financial navigation service compared to other potential navigation sources (20-22). Half of NCORP practice groups reported financial navigation occurred through a financial navigator designated specifically for cancer patients. NCORP practice groups that had a cancer-specific financial navigators designated for cancer patients is encouraging both for cancer care delivery and for intervention design and testing. Existing data suggest providing a cancer-specific navigator may be a promising intervention to help standardize and coordinate interventions to address financial hardship early into cancer care (23-25). The use of cancer-specific financial navigators in NCORP practice groups suggests NCORP practice groups have capacity to test financial hardship interventions currently being piloted or tested in randomized trials (24-28).

A supporting aim of this study considered whether NCORP practice groups serving patients who may be most vulnerable to financial hardship offer services to assess and assist these patients. We examined differences based on safety-net designation, Critical Access Hospitals, proportion of patients on Medicare/Medicaid, uninsured/charity care, proportion of racial/ethnic minority patients served, as well as broader practice group characteristics such as region and availability of inpatient services. Practice groups with more than 10% of new cancer patients who were enrolled in Medicaid or dual Medicaid/Medicare enrolled were more likely to screen for financial concerns, but not more likely to offer navigation.

Across both outcomes – screening for financial concerns and offering a dedicated financial navigator for cancer patients—the one factor that was consistently related to outcomes in adjusted models was the practice group's composition of racial and ethnic minority patients. Practice groups that reported at least 30% racial and ethnic minority cancer patient composition were less likely to screen for financial concerns and have a cancer-specific financial navigator. Multiple studies show Black and Hispanic cancer patients experience more financial hardship compared to White cancer patients (29-32). Navigation is recognized as a critical method to help reduce cancer care inequities among racial and ethnic minority patients (33). Our financial navigator finding highlights a critical disparity in cancer care delivery practices that needs to be addressed through investment of resources.

This study raises several important future research directions. First, building on the Landscape survey's focus on breadth of services, future studies should evaluate the quality, reach, and implementation of financial screening and services. Evaluating which financial screening measures are used and when, mapping financial navigation sources, and assessing financial navigator roles and responsibilities is a logical next step, especially as financial navigator responsibilities can vary (20-22). An important component of such a study would be to identify which patients within a practice group are not reached by financial navigation and why. Related to this, although the Landscape survey overcame a major limitation of existing data on financial hardship by focusing on the practice level, multilevel assessment and intervention studies are clearly needed (3). Engaging multiple stakeholders – patients, informal caregivers, providers, administrators, and policy makers - will be necessary to identify effective and scalable financial hardship interventions. Policy is perhaps the most critical component to evaluate and intervene upon. Most existing interventions have focused on patient education, navigation, and cost transparency (24-28), but do not address the underlying problem of high oncology treatment costs. Changes in federal and state policy are needed to address this fundamental cause of financial hardship (e.g., state laws to ensure equivalent coverage for oral anticancer therapies (3,34)).

Limitations

Although this multi-site, community cancer study addresses knowledge gaps in existing literature (e.g., single site, academic medical center settings), the NCORP Landscape Assessment is not a nationally representative sample of community practices. This is a descriptive, cross-sectional survey study that relies on practice self-report. A follow up study using process evaluation (e.g., direct observation, medical record review, key informant interviews, etc.) would help provide more objective data on the implementation of financial screening and service provision within NCORP. Such a study would help address another limitation of this study, which was that the Landscape survey focused on breadth of cancer care delivery services provided and was not designed to evaluate quality and reach of individual services. Related to this, we allowed practice groups to indicate multiple potential sources of financial navigation. Question wording precluded examining and reporting the percentage of practice groups with different combinations of potential financial navigation sources. The future research directions we described above are important and logical next steps to build on this study's results. Finally, the Landscape survey, though the largest survey of community oncology practices to date, had limited Northeast community oncology

practice representation. Northeast representation in this study was similar to its representation within NCORP. Still, this limited our ability to draw conclusions about regional differences. Related to this, we are unable to compare characteristics of our participating practices with practice characteristics of NCORP practice groups that did not participate in the Landscape assessment (no comparable database exists) or community oncology practice groups outside of the NCORP network.

Conclusions

Limitations notwithstanding, this study is the first identifying financial hardship assessment and intervention capacity in diverse community oncology practices. Data suggest financial hardship screening and navigation services within community oncology practices involve multiple clinical and para-clinical services (e.g., social work, outside counseling or case management, and/or dedicated navigators). Future efforts may more comprehensively characterize financial navigation screening pathways and processes. NCORP practice groups serving a substantive proportion of racial/ethnic minorities may require additional support to provide financial screening and navigation services. Findings also suggest capacity within NCORP practice groups to conduct cancer care delivery research to improve financial navigation for patients and their families. As cancer care costs continue rising, it will be critical to concomitantly encourage research informing current and novel interventions addressing financial hardship among diverse patient populations.

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Abbreviations:

NCORP	NCI Community Oncology Research Program
EHR	electronic health record

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Table 1.

Characteristics of Participating NCI Community Oncology Research Program (NCORP) Oncology Practice Groups

	Ν	% ^a
Oncology Practice Group Characteristics		
Number of new adult cancer cases/year 1000 b	121/218	56
Region	227	
Midwest	113	50
Northeast	14	6
South	52	23
West	48	21
Includes an outpatient oncology clinic in or on a hospital campus	186/227	82
Includes a free-standing oncology clinic or a Private/Group Practice	131/227	58
Includes inpatient services	186/225	83
Critical Access Designation ^C	46/222	21
Self-identified Safety Net	56/225	25
Characteristics of Oncology Patients within Practice Groups^d		
>10% of New Cancer Patients are either Medicaid or Dual Medicaid/Medicare Enrolled	94/212	44
>10% of New Cancer Patients Receive either Charity Care or are Uninsured	22/211	11
30% of New Cancer Patients are Hispanic and/or Racial Minority	56/212	26

 a Percentages are calculated out of the total number available for each characteristic.

^bExcludes pediatric cases.

^cCritical Access- have 25 or fewer acute care inpatient beds and are generally located more than 35 miles from another hospital

^dSpecified as patients diagnosed and/or receiving their first course of cancer treatment at that facility

Table 2.

Proportion of NCORP Oncology Practice Groups Screening for Financial Concerns and Offering Various Sources of Financial Navigation Services

	Ν	% ^a		
Financial Screening Practices				
Financial Screening Process is in Place for Cancer Patients	159/221	72%		
Method for Screening (for practice groups screening n=159; could check all that apply)				
Patient Intake Form	108/159	68%		
Other	73/157	47%		
Vitals or other form completed by nurse or nurse assistant	45/156	29%		
Questions in EHR	44/157	28%		
Sources of Financial Navigation Services (could check all that apply)				
Financial Navigator or Counselor Specific to Cancer Patients	110/219	50%		
Social Worker	147/221	67%		
Referred to Outside Counseling or Case Management Service	114/221	52%		
Referred to American Cancer Society	104/108	87%		
Referred to other patient advocacy group	59/117	51%		
Billing Staff	107/220	49%		
Financial Navigator or Counselor that is not Dedicated to Cancer Patients	79/220	36%		
None of the above	7/214	3%		

^aPercentages are calculated out of the total number available for each characteristic.

NCORP, NCI Community Oncology Research Program; EHR, electronic health records

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Table 3.

Proportion of NCORP Oncology Practice Groups Screening for Financial Concerns and Offering Dedicated Financial Navigation for Cancer Patients by Practice and Patient Characteristics.

	Screens for Financial Concerns (N=159)		Has Dedicated Financial Navigator for Cancer Patients (N=110)	
	N (%)	р	N (%)	р
Number of new adult cancer cases/year		1.00		0.04
<1000	87 (73%)		51 (44%)	
1000	71 (74%)		56 (58%)	
Region		0.05		0.03
Midwest	82 (75%)		63 (59%)	
Northeast	6 (43%)		3 (21%)	
South	40 (78%)		22 (43%)	
West	31 (66%)		22 (47%)	
Includes an outpatient clinic in or on a hospital campus		0.43		1.00
Yes	134 (73%)		91 (50%)	
No	25 (66%)		19 (50%)	
Includes a free-standing clinic or a Private/Group Practice		0.23		1.00
Yes	88 (69%)		63(50%)	
No	71 (76%)		47 (51%)	
Includes inpatient services		0.07		0.86
Yes	137 (75%)		91 (50%)	
No	21 (58%)		19 (53%)	
Critical Access Designation		0.04		0.32
Yes	38 (84%)		26 (58%)	
No	120 (69%)		83 (48%)	
Self-identified Safety Net		1.00		0.76
Yes	41 (73%)		29 (53%)	
No	117 (72%)		80 (49%)	
Percentage of New Cancer Patients that are either Medicaid or Dual Medicaid/Medicare Enrolled		0.12		0.27
0-10%	80 (68%)		64 (55%)	
>10%	74 (78%)		44 (47%)	
Percentage of New Cancer Patients receiving either Charity Care or are Uninsured		0.45		0.82
0-10%	135 (72%)		12 (55%)	
>10%	18 (82%)		95 (51%)	
Percentage of New Cancer Patients that are Hispanic and/or Racial Minority		0.29		< 0.01
<30%	118 (76%)		87 (57%)	
30%	38 (68%)		20 (36%)	

Table 4.

Adjusted Odds Ratios for Characteristics associated with NCORP Oncology Practice Groups Screening for Financial Concerns and Offering Financial Navigation

	Screens for Financial Concerns		Has Dedicated Financial Navigator for Cancer Patients	
	OR (95% CI)	Р	OR (95% CI)	Р
Region *				
Midwest vs. Northeast	3.59 (0.76-16.89)	0.15	-	-
South vs. Northeast	7.06 (1.21-41.10)	0.03	-	
West vs. Northeast	4.83 (0.82-28.61)	0.10	-	
South vs. West	1.46 (0.36-5.94)	0.90	-	
Midwest vs. South	0.51 (0.14-1.83)	0.53	-	
Midwest vs. West	0.74 (0.21-2.67)	0.93	-	
Medicaid/Dual Medicaid Medicare	-			
>10% vs. 10% of New Cancer Patients are Medicaid or Dual Medicaid/ Medicare Enrolled	2.81 (1.22-6.48)	0.02	-	-
Racial or Ethnic Minority Proportion				
<30% vs. 30% of New Cancer Patients Hispanic or a Racial Minority Group	3.91 (1.44-10.61)	<0.01	2.37 (1.26-4.47)	<0.01

NCORP, NCI Community Oncology Research Program.

Adjusted odds ratios with confidence intervals and p-values from resulting logistic models are presented. For post-hoc comparisons by region, Tukey-Kramer adjusted odds ratio and p-values are presented.

Overall p-value for Region=0.04.

Only variables retained in the model are presented. Only racial/ethnic minority composition of cancer patients served was retained in the financial navigator model.