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Factors Influencing Adherence to Recommended Colorectal Cancer Surveillance: Experiences and Behaviors of Colorectal Cancer Survivors

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Abstract

The number of colorectal cancer (CRC) survivors in the USA is increasing and factors associated with CRC surveillance require attention. This study examined the role of personal, provider, and practice-level factors on CRC survivor care surveillance experiences and outcomes. A telephone survey, informed by the Chronic Care Model, was conducted over a 1-year period with 150 CRC survivors identified via the South Carolina Central Cancer Registry. Participants were ages ≥ 21 years and diagnosed with stages I–III CRC within 1.5 years of study enrollment. Data were analyzed using descriptive statistics and logistic regression. Adherence was defined as receipt of surveillance colonoscopy at 13 months post-CRC surgery, as recommended by evidence-based guidelines. The majority of participants were male (55%) and white (86%), with a median age of 65 years (range 25–89). Almost half (43%) had attained a high school degree or less. Cancer stage was fairly evenly distributed, and 58% had received treatment by surgery alone (provider-level factor). Few participants (56%) received a survivorship care plan (practice-level factor), and adherence to surveillance colonoscopy was lowest (36%) among participants with more than one comorbidity (personal-level factor). Logistic regression models showed that the only significant effect of personal, provider, or practice-level factors on CRC surveillance adherence was related to type of health insurance coverage (private/HMO vs. other; $p = 0.04$). This is one of the first studies to evaluate CRC surveillance in a socioeconomically diverse sample. The only associations found among the examined factors and adherence were related to type of health insurance coverage. Participants with private/HMO health insurance were significantly more likely than participants with "other" health insurance coverage types (i.e., none, Medicare without supplement, Medicare with supplement) to be adherent to the 13-month colonoscopy. Therefore, future education strategies and patient navigation interventions could focus on identifying and overcoming multi-level barriers to CRC surveillance services.

Keywords Colorectal cancer · Surveillance · Adherence · Colonoscopy

Introduction

Colorectal cancer (CRC) is the 3rd most frequently diagnosed cancer in the United States (US) [1], where in 2017, 135,430 new cases of CRC were diagnosed [2]. The good news about this cancer is that CRC death rates are declining for men and women, with a significant 49% decrease in mortality between 1976 and 2012 [2]. According to the American Cancer Society, more than 1 million CRC survivors are currently living in the US [2].

The large and growing number of CRC survivors in the US highlights the need to evaluate their adherence to follow-up care recommended by evidence-based guidelines developed by professional societies. After treatment of an initial CRC diagnosis, surveillance leads to early detection of recurrences or second primary CRCs and also enhances likelihood of survival for patients with stage II–III CRC [1, 3, 4].

CRC surveillance is defined as office visits, carcinoembryonic antigen (CEA) testing, surveillance colonoscopy, and adherence to surveillance-related lifestyle recommendations to reduce risk of CRC recurrence. Colonoscopy is the first-choice procedure for clinical surveillance after curative-intent CRC resection, followed by office visits and lifestyle factors. A number of studies highlight the link between surveillance-related lifestyle factors (maintaining a healthy weight, being physically active, not smoking, and limiting alcohol use) and CRC recurrence risk. A previous

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meta-analysis showed the efficacy of surveillance in CRC survivors. However, few studies have assessed adherence behaviors in CRC survivors.

Indeed, Paulson et al. [1] recently completed a retrospective analysis of patients identified in the Survival, Epidemiology, and End Results (SEER)-Medicare database. All of the patients had received resection of stage I–III CRC from 2001 to 2009. The analysis included 23,990 colon cancer cases and 5665 rectal cancer cases. These investigators found that while rates of office visits and colonoscopy were high throughout the study period, rates of CEA surveillance remained low (even for patients with stage III CRC). Rates of computed tomography (CT) imaging increased during the study period but did not meet the minimum National Comprehensive Cancer Network (NCCN) guidelines for this form of surveillance. In contrast, many stage I survivors were found to receive intensive surveillance via non-guideline concordant CEA testing and CT imaging. These data show that underuse of guideline-adherent surveillance for CRC survivors is widespread and continues to be a challenge. The limited published studies show that individual characteristics linked to low rates of CRC surveillance include African American race, older age, and lower income [5–7].

Additional research is needed to uncover the underlying factors that contribute to these low surveillance adherence rates. Further, in a recent review of multi-level factors contributing to CRC surveillance adherence, Carpentier et al. [7] noted that there is a need to conduct studies that assess modifiable determinants of surveillance at the patient, provider, and healthcare system levels. While these investigators note the difficulties of conducting studies that do not rely on administrative data, they argue that only after modifiable determinants of surveillance have been identified can intervention strategies and messages to increase adherence be conceived, conducted, and evaluated [7].

Lack of physician recommendation is the most common reason reported for not receiving CRC screening, although evidence is limited [5]. Follow-up may be confusing, and therefore, communication between survivors and their physicians about surveillance care warrants further inquiry.

Guiding Framework and Study Purpose

The conceptual framework for this study reflects an ecological orientation in which an individual's behavior is both impacted by and impacts factors on several levels of influence, as well as the Chronic Care Model [8, 9] which emphasizes the interpersonal and environmental context of medical care. This research also incorporates constructs from health behavior theories [10–12] emphasizing self-efficacy [10] and perceived control [13, 14]. The purpose of this study was to examine the multi-level factors influencing receipt of guideline-directed surveillance care among CRC survivors. Specifically, the role of personal-level factors (e.g., health status, knowledge, attitudes, demographic characteristics), provider-level factors (e.g., physician-patient and specialist-primary care communication), and practice-level factors (e.g., health care use, insurance) on CRC surveillance adherence were examined.

Methods

Institutional Review Board Approval

Institutional Review Board (IRB) approval to conduct the study was obtained by the Medical University of South Carolina (MUSC) IRB as well as by the South Carolina Department of Health and Environmental Control (DHEC) IRB. Following the receipt of IRB approval, study participants were recruited by employing the following protocol.

Sample and Recruitment

This study presents the design and results of a statewide, registry-based telephone survey conducted over a 1-year period (February 2013 to January 2014) to systematically examine barriers and facilitators of surveillance care. The sample included CRC survivors who were residents from all counties of South Carolina. The data source for potential participants was the statewide South Carolina Central Cancer Registry. It is a population-based registry of cancer cases with a diagnosis date after December 21, 1995 [15]. The registry was designed to provide statistical information related to the incidence and prevalence of cancer and cancer mortality in South Carolina. A three-step process was followed to recruit patients from the cancer registry (sending a letter to each identified patient's physician of record to request permission to contact the patient, sending a letter to each patient whose physician gave permission for the patient to be contacted, and mailing a study survey to each patient who agreed to be contacted) [16].

The study staff contacted patients who did not return the mailed survey to schedule a telephone interview to complete the survey. When the patient was reached by telephone, the study staff provided a description of the study and asked the patient for verbal consent to administer the survey over the telephone. The survey administration was completed at that time if the patient had the time to do so. If not, the study staff scheduled the telephone administration of the survey for a later date.

During the telephone interview/scheduling process, the study staff used a standardized script to explain study details, answer questions, and confirm consent for the telephone survey using contact logs to document all calls, as well as the status of the mailed survey, missed appointments for those

completing the survey by telephone, call-backs, messages left, and survey completion. To maximize the likelihood of successful contact with each identified cancer registry patient, MUSC staff employed previously successful tracking strategies to obtain current working telephone numbers of patients, including asking the cancer registry staff to obtain this information from the most recent medical record of each patient in the registry and by employing online tracking sites, such as https://www.ussearch.com/ , to obtain valid telephone numbers [17]. In addition, when the study staff first made telephone contact with each patient, they requested an alternative telephone number such as a mobile telephone number or the telephone number of a friend or relative who could locate the patient's whereabouts. The study survey data were collected and managed using the Research Electronic Data Capture (REDCap) system, a secure, Web-based data management system [18].

Survey Description and Data Analysis

The investigators examined personal-level, provider-level, and practice-level factors that may play a role in adherence to surveillance care in CRC survivors. The survey was based on items from previously validated patient surveys [8, 19, 20] as well as additional items from domains that were developed by the researchers following a review of the literature.

Adherence was defined as receipt of surveillance colonoscopy at 13 months post-CRC surgery, as recommended by evidence-based guidelines developed by professional societies. Three binary variables were constructed for adherence to guideline-recommended CRC surveillance care (≥ 1 colonoscopy within 13 months of surgery, ≥ 1 office visit, ≥ 1 CEA test) from the relevant cancer registry and survey measures. Participants either met the guideline for each recommendation or did not. Percent adherence was calculated for each of the three adherence items for the various demographic, clinical, and psychosocial/other factors. Logistic regression was used to estimate odds ratios (OR) of colonoscopy adherence for each factor of interest. These models were performed first one factor at a time, and then adjusted for age, sex, stage, insurance, and number of comorbid conditions (0, 1, > 1).

Results

A total of 483 CRC registry patients were identified: 339 colon cancer survivors, 118 rectal cancer survivors, and 26 who were survivors of cancer of the rectosigmoid junction. Of the 483 patients identified, 420 could be contacted by the cancer registry staff of which 49 participants passively refused to participate and 130 participants opted out of study participation.

In the initial pool of 483 identified cancer registry patients, a lower percentage of African Americans were identified in comparison to the number of whites who were identified: 76% were white and 23% were African American. Among the 420 patients who could be contacted by the cancer registry staff, 49 participants passively refused to participate (63% white, 33% African American) and 130 participants opted out of study participation (83% white, 16% African American).

Therefore, a total of 241 patients opted into the study, of whom 80% were white and only 20% were African American, providing a smaller pool of African Americans to recruit to the study. Of the 192 whites who opted into the study, 67% completed the survey, and of the 48 African Americans who opted into the study, only 40% completed the survey. Although 241 patients initially opted into the study, the analysis was limited to 150 patients as 91 patients were excluded due to passive refusal ($n = 13$), active decline ($n = 16$), ineligibility ($n = 23$), or due to the study recruitment goal being met prior to survey completion ($n = 39$).

Among the 13 patients who passively refused to participate in the survey after opting into the study and agreeing to be contacted by the study investigators, 54% were white and 46% were African American. Of the 16 patients who actively declined survey participation after opting into the study, 81% were white and 23% were African American. Among the 23 patients who were ineligible to complete the survey after opting in, 65% were white and 35% were African American.

Thus, the investigators obtained data from the South Carolina Central Cancer Registry files for 150 patients who were diagnosed with stages I–III CRC within 1.5 years of study enrollment. All of the identified patients were ages 21 years or older at study enrollment. Their contact information, including telephone number and address, was obtained from the registry, as well as their CRC treatment history of surgery, radiation therapy, and/or chemotherapy.

Patient's Personal-Level Factors

The survey response rate was 62.2%, producing a final sample size of 150 participants. Table 1 shows patient characteristics by adherence to the three clinical surveillance guideline procedures. In the study sample of 150 CRC survivors, 91% of participants were aged ≥ 51 years with a median age of 65 years (range = 25–89 years). The sample included slightly more females than males. Fourteen percent of the participants were African American. The majority (74%) of participants had less than a college education, and most (76%) had an overweight (25 to < 30 kg/m^2) or obese BMI (≥ 30 kg/m^2). Seventy-three percent of patients were diagnosed with colon cancer, whereas 19% were diagnosed with rectal cancer and 8% were diagnosed with both cancers. Cancer stage was fairly evenly distributed across the study sample (see Table 2). Nearly 3/4 of participants sought cancer-related information from one or more sources (Internet, friends, support group, etc.). Twenty percent of participants reported worrying about

Table 1 Personal, provider, and practice-level factors influencing CRC surveillance adherence

	Total $N = 150$ (N)	Column %	Colonoscopy $N = 142$ (% adherent; row %)		Office visits cancer doctor only $N = 146$ (% adherent; row %)		CEA test all blood tests $N = 148$ (% adherent; row %)	
			Yes	No	Yes	No	Yes	No
			55	45	92	8	73	27
Personal-level factors								
Sex								
Male	68	55	52	48	89	11	76	24
Female	82	45	58	42	95	5	71	29
p value			0.50		0.22		0.58	
Age (years)								
≤50	14	9	79	21	93	7	69	31
51–64	55	37	51	49	91	9	74	26
65–74	47	31	59	41	98	2	73	27
≥75	34	23	45	55	88	12	73	27
p value			0.18		0.27		0.98	
Race								
African American	21	14	43	57	95	5	55	45
White	129	86	57	43	92	8	76	34
p value			0.26		0.99		0.20	
Education								
<HS/GED	15	10	47	53	93	7	73	27
HS/GED	49	33	48	52	92	8	71	29
Some college/technical school	46	31	52	48	90	10	78	22
≥College graduate	40	26	69	31	95	5	69	31
p value			0.31		0.99		0.96	
Body mass index (BMI) (kg/m^2)								
< 18.5	1	< 1	0	100	100	0	100	0
18.5–24.9	34	23	57	43	94	6	69	31
25.0–29.9	53	35	51	49	90	10	70	30
≥30	62	41	58	42	93	7	77	23
p value			0.66		0.86		0.67	
Cancer diagnosis								
Colon cancer	110	73	52	48	93	7	71	29
Rectal cancer	28	19	59	41	96	4	82	8
Both	12	8	73	27	84	16	75	25
p value			0.38		0.39		0.57	
Cancer stage								
I	29	19	61	39	86	14	48	52
II	31	21	55	45	97	3	74	26
III	34	23	53	47	100	0	88	12
Something else/not sure	55	37	52	48	89	11	76	24
p value			0.70		0.12		0.01*	
Comorbidity count								
0	33	22	72	27	97	3	73	27
1	63	42	53	47	95	5	68	32
>1	54	36	47	53	87	13	79	21

Table 1 (continued)

		Total $N = 150$ (N)	Column %	Colonoscopy $N = 142$ (% adherent; row %)		Office visits cancer doctor only $N = 146$ (% adherent; row %)		CEA test all blood tests $N = 148$ (% adherent; row %)	
				Yes 55	No 45	Yes 92	No 8	Yes 73	No 27
	p value			0.08		0.20		0.91	
Sought information from ≥1 source									
No		41	27	50	50	88	12	78	22
Yes		109	73	57	43	94	6	71	29
	p value			0.57		0.61		0.64	
Follow-up care confidence									
Average < 4		49	33	54	46	92	8	75	25
Average ≥ 4		101	67	55	45	94	6	85	15
	p value			0.99		0.99		0.44	
Cancer worry									
Average < 4		120	80	52	48	92	8	74	26
Average ≥ 4		30	20	68	34	93	7	70	30
	p value			0.14		0.99		0.65	
Religion/faith/spirituality impacts the decisions the patient makes about follow-up care?									
Never		63	42	55	45	90	10	71	29
Rarely		9	6	75	25	89	11	67	33
Sometimes		7	5	43	57	100	0	57	43
Often		6	4	17	83	100	0	67	33
Always		65	43	57	43	94	6	78	22
	p value			0.27		0.85		0.65	
Provider-level factors									
Doctor communication quality with patient									
Average < 3		13	9	55	45	92	8	54	46
Average ≥ 3		137	91	55	45	93	7	75	25
	p value			0.99		0.99		0.11	
Patient received written summary about cancer care									
No		62	44	53	47	88	12	70	30
Yes		80	56	58	42	95	5	75	25
	p value			0.60		0.21		0.91	
Quality of care received by patient since completing treatment									
Poor		1	< 1	0	100	100	0	0	100
Fair		3	2	0	100	100	0	33	67
Good		17	12	56	44	100	0	59	41
Very good		50	34	56	44	88	12	78	22
Excellent		76	52	57	43	93	7	75	25
	p value			0.30		0.48		0.09	
Decision-making about cancer care:									
• Patient + family, no doctor input		11	7	40	60	91	9	45	55
• Patient + family, considering doctor input		45	30	67	33	96	4	76	24

Table 1 (continued)

		Total $N = 150$ (N)	Column %	Colonoscopy $N = 142$ (% adherent; row %)		Office visits cancer doctor only $N = 146$ (% adherent; row %)		CEA test all blood tests $N = 148$ (% adherent; row %)	
				Yes 55	No 45	Yes 92	No 8	Yes 73	No 27
• Patient + family + doctor decide together		79	53	49	51	92	8	72	28
• Doctor, considering patient + family input		9	6	57	43	75	25	89	11
• Doctor, little or no input from patient + family		6	4	67	33	100	0	100	0
	p value			0.33		0.29		0.15	
Practice-level factors									
Patient's insurance status									
Private		61	50	64	36	95	5	75	25
None		3	2	33	67	100	0	67	33
Medicare w/o supplement		24	20	61	39	91	9	92	8
Medicare with supplement		34	28	36	64	92	8	67	33
	p value			0.04*		0.74		0.12	
Patient has seen PCP at least once									
No		21	14	68	32	100	0	64	36
Yes		129	86	53	47	91	9	73	27
	p value			0.23		0.60		0.53	
Hard for patient to keep track of appointment									
No		138	92	53	47	92	8	72	28
Yes		12	8	75	25	100	0	81	19
	p value			0.23		0.60		0.51	
Patient's unmet needs									
0		117	78	55	45	92	8	70	30
≥ 1		33	22	55	45	94	6	82	18
	p value			0.99		0.99		0.27	
Patient told by doctor he/she needed regular follow-up care									
No		14	9	43	57	64	36	43	57
Yes		136	91	56	44	95	5	76	34
	p value			0.40		0.001**		0.02*	

CRC colorectal cancer, *CEA* carcinoembryonic antigen, *HS* high school, *GED* general education development, *PCP* primary care physician, *w/o* without

*Statistical significance at $p < 0.05$. **Statistical significance at $p < 0.01$

Table 2 Logistic regression modeling adherence to 1-year (13-month) colonoscopy

	N	Univariate OR (95% CI)	*p* value	Adjusted *p* value (adjusted for age, sex, stage, insurance, comorbidity count)
Personal-level factors				
Age				
< 65	69	1.0		
≥ 65	81	0.9 (0.4–1.7)	0.66	n/a
Sex				
Female	82	1.0		
Male	68	0.8 (0.4–1.5)	0.46	n/a
Race				
White	127	1.0		
African American	23	0.6 (0.2–1.4)	0.23	–
Education				
< HS/GED	15	1.0		
HS/GED	49	1.0 (0.3–3.4)	0.94	
>HS/GED	86	1.8 (0.6–5.5)	0.32	–
Cancer diagnosis				
Colon	110	1.0		
Rectal	28	1.3 (0.6–3.2)	0.50	–
Both	12	2.5 (0.7–11.7)	0.20	–
Cancer stage				
I/II	60	1.0		
III	34	0.8 (0.3–2.0)	0.68	n/a
Something else/not sure	55	0.8 (0.4–1.7)	0.52	n/a
Comorbidity count				
0	33	1.0		
1	63	0.4 (0.2–1.1)	0.08	n/a
> 1	54	0.3 (0.1–0.9)	0.03*	n/a
Body mass index (BMI) (kg/m^2)				
< 25	35	1.0		
≥ 25	115	1.0 (0.4–2.2)	0.99	–
Sought information from ≥ 1 source				
No	41	1.0		
Yes	109	1.3 (0.6–2.8)	0.46	0.70
Follow-up care confidence				
Average < 4	101	1.0		
Average ≥ 4	49	1.0 (0.5–1.9)	0.90	0.95
Cancer worry				
Average < 3	120	1.0		
Average ≥ 3	30	2.0 (0.8–4.9)	0.13	0.18
Family or friends encourage patient to get follow-up care				
Never, rarely, sometimes	36	1.0	0.65	0.51
Often, always	114	1.2 (0.5–2.6)		
Have at least one family member with cancer				
No	97	1.0		
Yes	53	1.6 (0.8–3.4)	0.16	0.27
Religion/faith/spirituality impacts the decisions the patient makes about follow-up care				
No	79	1.0		
Yes	71	0.9 (0.5–1.8)	0.76	0.99
Provider-level factors				
Patient received written summary about care plan				
No	62	1.0		
Yes	80	1.2 (0.6–2.4)	0.58	0.87
Doctor communication quality with patient				
Average < 3	13	1.0		
Average ≥ 3	137	1.0 (0.3–3.5)	0.98	0.86
Patient discussed long-term treatment side effects with doctor				
No	51	1.0		
At least once	97	1.0 (0.5–2.0)	0.96	0.44
Decision-making about cancer care				
Patient + family + doctor decide together	133	1.0		
	17	0.8 (0.3–2.3)	0.67	0.64

Table 2 (continued)

	N	Univariate OR (95% CI)	*p* value	Adjusted *p* value (adjusted for age, sex, stage, insurance, comorbidity count)
Patient + family or doctor decide with little or no input from each other				
Practice-level factors				
Patient's insurance status				
Private/HMO	60	1.0		
Other	90	0.48 (0.24–0.95)	0.04*	n/a
Cancer treatment				
Surgical resection alone	87	1.0		
Surgery + chemo	26	0.7 (0.3–1.9)	0.53	–
Surgery + radiation ± chemo	37	1.2 (0.5–2.6)	0.73	–
Dislike or cost of colonoscopy ever stopped patient from getting test?				
No	128	1.0		
Yes	22	1.0 (0.4–2.7)	0.99	0.90
Patient's unmet needs				
No	117	1.0		
Yes	33	1.0 (0.4–2.3)	0.98	0.65

OR odds ratio, *CI* confidence interval, *GED* general education development, *HS* high school, *HMO* health maintenance organization, *chemo* chemotherapy

*Statistical significance at $p < 0.05$

a CRC recurrence (avg. ≥ 4). For 43% of participants, religion/faith/spirituality always impacted the decision made about follow-up care, although among 42%, religion/faith/spirituality never impacted the decision.

Overall, CRC surveillance adherence rates were not high for any of the study participants for colonoscopy at 12 or 13 months (55%), but were 92% for office visits for cancer doctors and 73% for CEA tests. To become concordant with the NCCN-recommended surveillance guidelines, improvements would have to be seen for participants from all socio-demographic backgrounds. Across all stages of CRC, 39–48% of participants were non-adherent to surveillance colonoscopy at 13 months post-surgery, 0–14% were non-adherent to office visits with cancer doctors, and 12–52% were non-adherent to the CEA test. Most sociodemographic factors were not associated with adherence. However, among individuals who were adherent to CEA tests, significant differences were observed for cancer stage including stages I–III and those unsure of the stage ($p = 0.01$) (see Table 2). Participants with more than one comorbidity were less adherent to colonoscopy and cancer doctor office visits than those with one or zero comorbidities; however, they were more adherent to CEA tests.

Provider-Level Factors

Many participants (44%) reported never receiving a written summary describing their cancer care (see Table 1). Despite this, the large majority of participants (98%) rated the quality of their care since receiving treatment as good to excellent, and < 3% rated the quality of their care as fair or poor. For most participants (53%), decisions about cancer care were made with equal input from the family and doctor. Another 30% of participants made cancer care decisions with input from the family, taking the doctor's input into consideration. Seven percent of participants reported making cancer care decisions with their families without the doctor's input. Six percent of participants reported that their cancer care decisions were made by their doctors, with consideration of input from the patient and family. Finally, 4% of participants reported that their doctors made their cancer care decisions with little to no input from the patient or family. Written information about diagnostics was received by 90% of participants, whereas 94% received written information about treatments, and 85% received written information about follow-up care.

Practice-Level Factors

Insurance status differed significantly among those who were adherent to colonoscopy ($p = 0.04$) (Table 2). Half of the participants had private health insurance (50%), 28% had Medicare with supplemental insurance, 20% had Medicare without supplemental insurance, and 2% were uninsured (see Table 1). Only 9% of participants stated that cost has ever stopped them from getting a colonoscopy, and only 5% said that cost had ever stopped them from getting a CEA test. Slightly more than half of the participants had received surgery alone as their CRC treatment. Ninety-one percent of participants were told by their doctor that follow-up care was needed. Being told by the doctor that regular follow-up care was needed was also found to be significantly different for those adherent to office visits ($p = 0.001$) and CEA tests ($p = 0.02$). Follow-up care experiences of the study participants

(number of follow-up care doctors, location of care, barriers, whether received care plan, discussed long-term side effects, etc.) were also examined (data not shown). Since the end of treatment, the large majority reported seeing a primary care physician (PCP) or family doctor (86%, median number of visits = 3), cancer surgeon (83%, median number of visits = 3), medical oncologist (71%, median number of visits = 4), and gastroenterologist (62%, median number of visits = 1). Only 7% of participants reported seeing a radiation oncologist (median number of visits = 1), while 8% saw someone else for cancer care (median number of visits = 1.5) (data not shown). Further, most participants (62%) received follow-up care at the same place where cancer treatment was received. Additionally, 22% of participants reported having ≥ 1 unmet needs.

Adherence to 1-Year (13 Months) Colonoscopy

Table 2 shows that participants with private insurance were significantly more likely to adhere to the 13-month surveillance colonoscopy than those with other types of insurance coverage or without insurance in univariate analyses (OR = 0.48, 95% CI: 0.24–0.95). Also significantly more likely to adhere to the 13-month surveillance colonoscopy were those with no comorbidities compared with participants with > 1 comorbidity (OR = 0.3, 95% CI: 0.1–0.9). Following adjustment for age, sex, stage, insurance, and number of comorbid conditions, the associations were no longer significant. No other significant differences in adherence by personal-, provider-, or practice-level factors were observed in univariate or in multivariate analyses.

Discussion

In this study, we examined adherence to CRC surveillance guidelines and explored a comprehensive set of personal, provider, and practice-level factors in CRC survivors. We found that adherence to CRC surveillance (as measured by adherence to colonoscopy) was lowest among participants with more than one comorbidity. Few other factors were associated with non-adherence, suggesting that it may be important to consider all patients at high risk for non-adherence and provide screening for any unique barriers to follow-up care.

As a personal-level finding, 37% of the study participants were unsure of their stage of diagnosis. This result was somewhat disconcerting; however, the participants' lack of knowledge appeared to have no statistically significant impact on adherence to the 1-year colonoscopy and also did not appear to negatively impact their adherence to the office visits or CEA tests. Future research could be conducted to systematically evaluate the effect of knowledge and understanding of cancer stage at diagnosis on subsequent adherence to surveillance guidelines.

Continuing the discussion of personal-level findings, interestingly, the study results show that participants with more than one comorbidity were significantly less likely to be adherent to surveillance colonoscopy, perhaps because they were busy seeing a large number of providers due to their multiple comorbidities. These findings are consistent with the previous work in Manitoba, Canada conducted by Sisler et al. [21]. These investigators reviewed health administrative data for colonoscopy, liver imaging, and CEA testing from a cohort of 250 patients diagnosed with stage II or III CRC in 2004 who were alive 42 months after diagnosis [21]. The results from the Sisler et al. study show that adherence was lower in participants with higher levels of comorbidity. In a 2008 study, Cooper, Kou, and Reynolds [6] identified a cohort of 9426 patients aged 66 years and older diagnosed with adenocarcinoma of the colon or rectum from 2000 to 2001 using a linked tumor registry-claims database. After observation of the patients for 3 years after diagnosis, only 73.6% of patients in the cohort were found to have received a guideline-concordant surveillance colonoscopy [6]. Again, higher levels of comorbidity were associated with lower rates of receipt of surveillance colonoscopy.

As a provider-level finding, some participants in the present study may not have received adequate communication from their health care teams regarding a CRC survivorship care plan. The data from the present study, although not statistically significant, show that the majority of participants did not receive a survivorship care plan. In a recent study, Mollica et al. [22] examined linked data from the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) cancer registry program as well as the Medicare Consumer Assessment of Healthcare Providers and Systems (CAHPS) patient experience surveys (SEER-CAHPS). The final cohort in the Mollica et al. study included 314 CRC survivors diagnosed in 1999–2009 who were ages 66+ years at the time of surgical resection. All identified patients completed a CAHPS survey within 36 months of the diagnosis, and data from a subsequent 3-year observation period were evaluated. Mollica et al. discovered that high ratings of PCPs were positively linked to overall adherence to surveillance colonoscopy, CEA tests, office visits, and computerized tomography tests [22]. These findings suggest that the patient-provider relationship, a potentially modifiable factor, is important in enhancing adherence to CRC surveillance care. This relationship is especially important in CRC surveillance care, which requires communication among multiple specialists, including PCPs, oncologists, and potentially, surgeons.

As a practice-level finding, slightly more than half of the study participants had received surgery alone as their CRC treatment. This finding appears to be concordant with the NCCN CRC treatment guidelines for stage I–II colon cancer, which recommend that colon cancer patients diagnosed with stages I–IIA receive surgery alone, while colon cancer patients diagnosed with stages IIB–IIIC are recommended to receive surgery in addition to chemotherapy. Thus, the majority of the

patients in the study appear to have received guideline-concordant care.

Another practice-level finding is highlighted by the fact that only 2% of the study sample reported having no health insurance coverage. In this regard, the study sample may not have been representative of the majority of CRC patients. In a recent study, Parikh et al. [23] identified 10,692 patients who were diagnosed with CRC between 2004 and 2008. In this study sample, the investigators discovered that patients who were uninsured or who were covered by Medicaid received recommended adjuvant therapy at rates that were comparable to those of insured patients. However, the uninsured/minimally insured patients presented with later stage disease and had worse overall survival [23]. Based on these results, it is possible that if the present study had included a larger percentage of uninsured/minimally insured participants, different patterns of CRC surveillance adherence may have been seen.

Level of health insurance coverage also appears to have influenced adherence to CRC surveillance via colonoscopy. Participants with private/HMO health insurance were significantly more likely than participants with "other" health insurance coverage types (i.e., none, Medicare without supplement, Medicare with supplement) to be adherent to the 13-month colonoscopy. Specifically, participants with no insurance and those who had Medicare with supplemental insurance were least likely to receive CRC surveillance via colonoscopy over the study period. It is possible that these participants had more health insurance barriers than those with private/HMO health insurance, such as having a higher level of comorbidity, which may have prohibited them from receiving guideline-concordant CRC surveillance.

In regard to the initial CRC treatment that the participants received, the study analyses revealed that a small number of the participants diagnosed with colon cancer may have been overtreated. The NCCN guidelines that were in place during the data collection period recommended that patients with stage I colon cancer should receive only surgical resection [24]. Based on these guidelines, patients with stage I colon cancer should have received surgical resection alone, without any adjuvant therapy. However, in the study sample, based on self-reported data that were confirmed by actual cancer registry data, two participants with stage I colon cancer received chemotherapy and/or radiation therapy in addition to receiving surgical resection. The NCCN guidelines also recommended that stage II colon cancer patients should have received either surgical resection alone (if they were diagnosed with stage II low risk CRC) or surgical resection and chemotherapy (if they were diagnosed with stage II high-risk CRC). In the study sample, one participant received surgical resection, chemotherapy, and radiation therapy. For stage III colon cancer, the NCCN guidelines recommended that patients should have received surgical resection and chemotherapy. However, in the study sample, three stage III colon cancer patients received surgical resection, chemotherapy, and radiation therapy, indicating potential overtreatment.

The study analyses also revealed that a small number of the study participants diagnosed with colon cancer may have been undertreated. Receipt of surgical resection was a prerequisite for the sample selection, so all of the participants had received surgical resection. However, according to the NCCN guidelines, stage III colon cancer patients were recommended to receive surgical resection and chemotherapy. In the study sample, seven participants received resection alone, without also receiving chemotherapy, which indicated potential undertreatment. Taken together, these findings suggest that clinicians tended to err toward overtreatment rather than undertreatment in the patients who were diagnosed with stage I–II colon cancer, and tended to err toward undertreatment of stage III colon cancer patients.

Limitations and Strengths

The investigators acknowledge several study limitations. First, the study was conducted in only one state. South Carolina, which has high poverty rates, and which rejected the Medicaid expansion waiver for the Affordable Care Act, may not be representative of other states in the US. It is possible that the low CRC surveillance adherence rates seen in the present study are higher in other states. However, other investigators who evaluated national data have shown that even in insured populations, wide variations are seen in the use of CRC surveillance care [1, 25]. Indeed, Salloum et al. [25] noted in their study of CRC survivors from four large, non-profit, integrated health systems in Seattle, WA; Detroit, MI; Denver, CO; and Portland, OR, that only 50% of the study participants received recommended surveillance tests.

A second limitation is that the response rate was only 62.2%. Recruitment processes and outcomes are described in the methods and results, as well as in the investigators' previously published paper [16]. The response rate is likely a result of the IRB's requirement that participants opt into the study rather than opt out of the study. In the opt-in strategy, participants were required to do something active to be contacted by the researchers; in this case, the participants were required to be contacted by the cancer registry staff and give their permission to be contacted by the researchers. In contrast, in opt-out strategies, participants may be directly contacted by the researchers and have the option to decline participation when contacted. This form of active consent using an opt-out strategy has led to lower response rates in other studies as well [26, 27].

A third limitation is the low representation of African Americans in the study (14%). In South Carolina, African Americans comprise 30% of the general population, and also represent a similar proportion of the CRC cases in the state [28]. As compared to the general population, multiple call

attempts to potential African American participants were needed for successful recruitment [16].

Additionally, the Cronbach alphas of several of the investigator-adapted measures were low. Therefore, these measures require further development and testing in future studies.

Despite some limitations, the study has a number of strengths, including the availability of statewide stage I–III CRC surveillance data, providing a large sample size for analysis (150 cases: 110 colon cancer cases, 28 rectal cancer cases, and 12 rectosigmoid junction cancer cases). Although the proportion of African Americans participating in the study was only 14%, it was possible to compare racial differences in outcomes. In the study sample, cancer stage was fairly evenly distributed across the participants. According to the American Cancer Society [29], only 39% of CRC patients in the US are diagnosed with localized disease. In the present study, the sample included CRC survivors with both localized and regional disease. Also, educational attainment levels were fairly evenly distributed across the study participants. Therefore, the study results may have broad applicability to CRC survivors of different non-metastatic stages. Excluding the participants ($n = 55$, 37%) who were unsure of their stage of diagnosis, 63% of the remaining participants ($n = 95$) in the study sample were diagnosed with stage I–II CRC (41 of whom were colon cancer patients).

Conclusions

In conclusion, this study is one of the first to evaluate CRC surveillance in a socioeconomically diverse sample, as indicated by the fact that 43% of the sample had attained a high school diploma or less as their highest level of education. While NCCN guidelines appeared to have been followed for the vast majority of participants, some were over/under-treated. The study results suggest that in this population, few participants had received a survivorship care plan, and adherence to surveillance colonoscopy was lowest among participants with no insurance and those who had Medicare with supplemental insurance, as well as those who had multiple comorbidities.

Taken together, the findings suggest that CRC survivors could benefit from having patient navigators, who could serve as intermediaries between the multidisciplinary clinical care team and CRC survivors. The navigators could help to help to overcome multi-level barriers (i.e., systemic, provider-level, and patient-level barriers) to ensure that each patient receives a survivorship care plan and could also develop strategies to overcome barriers to accomplishing the goals of the survivorship care plan. In this manner, each patient's risk of subsequent CRC recurrence could be significantly reduced and the likelihood of early detection of a recurrence could be substantially enhanced.

In addition to a potential navigation intervention to enhance CRC surveillance care, an educational intervention for providers might also be helpful. Given the need for communication among the different types of specialists who are involved in CRC surveillance care, an educational intervention could include PCPs and specialists such as medical oncologists, radiation oncologists, and surgeons. These providers could potentially benefit from an educational intervention that includes continuous quality improvement (CQI) and communication skills training [30].

A similar intervention was employed successfully by Dolan et al. (2015) in an attempt to improve CRC screening discussions between providers and African American and Latino patients with low or limited health literacy levels [30]. In the Dolan et al. intervention, the CQI component included audits of medical records as well as feedback on CRC screening recommendations and completion of CRC screening tests. The communication skills component of the Dolan et al. intervention consisted of the teachback method, using simplified language, and incorporating visual aids. These investigators discovered that compared to usual care and a physician-only intervention, the CQI and communication skills training intervention led to increased rates of CRC screening discussions.

Given the fact that the Dolan et al. (2015) CRC educational intervention for providers produced successful results in a medically underserved population with low health literacy, it has a high likelihood of success in the general population as well [30]. Future studies could evaluate the effectiveness of the educational intervention in increasing rates of CRC surveillance adherence in a random sample of diverse CRC survivors.

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Compliance with Ethical Standards

Institutional Review Board Approval Institutional Review Board (IRB) approval to conduct the study was obtained by the Medical University of South Carolina (MUSC) IRB as well as by the South Carolina Department of Health and Environmental Control (DHEC) IRB. Following the receipt of IRB approval, study participants were recruited by employing the following protocol.

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