Surveillance Instructions and Knowledge Among African American Colorectal Cancer Survivors

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Abstract

Introduction: African Americans are less likely than other racial/ethnic groups to receive appropriate surveillance, an important component of care to achieve better long-term outcomes and well-being after colorectal cancer (CRC) treatment. This study explored survivors' understanding of surveillance instructions and purpose.

Patients and Methods: Interviews with 60 African American CRC survivors were recorded and transcribed. Compliance with surveillance guidelines was defined by disease stage and self-reported tests. Four coders (blind to compliance status) independently reviewed transcripts. Frequency of themes was reported by compliance status.

Results: Survivors (4 to 6 years postdiagnosis; women, 57%; age ≥ 65 years, 60%; rural location, 57%; early-stage

disease, 62%) were 48% noncompliant. Most survivors reported receiving surveillance instructions from providers (compliant, 80%; noncompliant, 76%). There was variation in recommended frequency of procedures (eg, every 3 or 12 months) and in importance of surveillance stressed by physicians. Most survivors understood the need for follow-up (compliant, 87%; noncompliant, 79%). Lack of knowledge of/interest in surveillance was more common among noncompliant individuals (compliant, 32%; noncompliant, 52%).

Conclusion: Patients' limited understanding about the importance of CRC surveillance and procedures may negatively affect compliance with recommendations in African American CRC survivors. Clear and enhanced communications about post-treatment recommendations in this population are warranted.

Introduction

The purpose of surveillance after primary treatment for colorectal cancer (CRC) is to evaluate treatment complications, tumor recurrences, and new primary cancers or metastases. Procedures include physical examinations, blood tests, colonoscopy, and computed tomography scans (for those with stage III disease or those with stage II disease at high risk of recurrence).¹⁻⁴ Guidelines vary in the timing of procedures (eg, colonoscopy within 1 year of surgical resection or during first year and again within 3 years).¹

Studies report low rates of compliance with surveillance recommendations.⁵ Only approximately half of CRC survivors diagnosed from 2000 to 2008 in four US health integrated systems received recommended surveillance care within 18 months of treatment.⁶ Among Cancer Care and Outcomes Research and Surveillance (CanCORS) consortium participants from 2003 to 2005, approximately half underwent a colonoscopy within 14 months of surgery.⁷ Moreover, significant differences exist in surveillance between African American and white CRC survivors in receipt, timing, and type of tests received, with approximately 10% fewer African Americans receiving surveillance as recommended.⁸⁻¹¹ Reasons why African Americans in particular do not comply with recommended surveillance are not clear.

Physician-patient communication is a key domain to consider.¹² Physicians need to communicate the importance and pro-

cess of surveillance in a way that patients can understand. Among breast cancer survivors, lack of information about mammography surveillance was a critical barrier to compliance with surveillance guidelines.¹³ For CRC surveillance, the existence of several guidelines may leave physicians unclear about what to recommend and may result in unclear communications to patients and in physicians not following guidelines at all.¹⁴ Only 30% of surveyed colorectal surgeons reported following surveillance guidelines,¹⁵ and only 50% of primary care physicians were confident that they were following standard guidelines.¹⁶ Therefore, understanding what patients were told about surveillance, and what they understood about its purpose and process, is fundamental to address poor compliance with guideline-recommended processes.

In the Y So Low (Reasons for Low Follow-Up in Black CRC Patients) study, we interviewed African American CRC survivors to investigate why they may or may not comply with surveillance guidelines. One of the goals was to understand what survivors recalled and understood about the instructions given by providers at the end of treatment and about the explanation of the purpose of surveillance. In this article, we report on these themes and the survivors' complex context in which instructions were delivered and assimilated.

Patients and Methods

The University of Alabama at Birmingham and the University of Maryland approved the study protocol, and participants pro-

vided informed consent. African Americans diagnosed with stages I to III CRC from 2003 to 2007 were invited to participate in 1-hour long interviews.

Participants were recruited among survivors who participated in the Deep South site of the CanCORS consortium^{17,18} and from the Alabama Statewide Cancer Registry (ASCR). African American CanCORS participants who completed surveys at baseline (within approximately 4 months of diagnosis) and follow-up (11 to 13 months postdiagnosis) were eligible to participate ($n = 98$). Sixty-two were contacted, 58 completed a screening survey, and 55 agreed to participate. Among 989 eligible survivors from ASCR, 399 were randomly selected and contacted, 150 completed a screening survey (249 were deceased, were ineligible, or had disconnected telephone numbers), and 73 agreed to participate. Interviews proceeded until saturation was reached among CanCORS and ASCR participants separately.

The screening survey questions were aimed at determining compliance with surveillance recommendations. Compliance status was as follows: for stages I to III disease, $\geq$ two visits per year in the first 3 years post-treatment and $\geq$ one colonoscopy since surgical resection; for stages II to III disease, also $\geq$ one computed tomography scan since surgical resection.

Interviews were conducted in the participants' homes or in another place of their choice. Participants received \$50 at the end of the interview. One trained interviewer and one note taker conducted the interview following a guide containing topics chosen based on (1) literature on barriers to CRC screening and surveillance and on theoretic models of health behavior and access to care^{12,19,20}; (2) input from an advisory panel of seven CRC survivors who shared their treatment experience with the investigative team; and (3) a CanCORS data analysis of the 58 CanCORS participants who responded to our screening survey. Topics were (1) knowledge about surveillance requirements (ie, understanding what patients were told after completing primary treatment, what instructions they received about surveillance, what they understood about purpose of surveillance, and whether they were confident they knew what to do for follow-up); (2) treatment experience (ie, methods of finding out about having cancer, treatments received, satisfaction with care, relationship with physicians and other providers, and role in decision making); (3) quality of life (ie, survivors' limitations that may prevent them from going to physician and obtaining surveillance tests); and (4) barriers and facilitators (ie, understanding structural and health care system organizational level barriers, accessibility of services and specialist care, available support, and other personal-level factors).

Interviews were recorded and transcribed verbatim. A codebook was developed based on an initial transcript review using an iterative process. Investigators independently reviewed transcripts and developed a preliminary list of codes. All codes were merged together and discussed to obtain a final list. The codebook included (1) code name (ie, theme emerging from transcripts), (2) code definition, (3) examples of text to represent the code, and (4) exclusion criteria (ie, specific examples of when code did not apply). Two pairs of coders independently re-

viewed the transcripts and applied selected codes using NVivo software (QSR International, Doncaster, Victoria, Australia). Coders were blind to interviewees' compliance status. Each pair of coders reviewed six transcripts (10%), compared their coding, and discussed discrepancies until they were confident that coding was comparable ($\kappa > 0.70$). Coders then applied the codes to the remaining 54 transcripts. Emerging themes were identified considering the frequency of codes among compliant and noncompliant responders, and text representative of the codes was selected for presentation in this article. Characteristics, self-reported use of surveillance procedures, treatment experience, and other findings in compliant and noncompliant responders were compared using a two-sided Pearson χ^2 or Fisher's exact test, using $\alpha = 0.20$ as the statistical significance level given the sample size (SAS software, version 9.2; SAS Institute, Cary, NC).

Results

Of the 60 African American CRC survivors interviewed, approximately 57% were women, 60% were age ≥ 65 years, 38% had stage III disease, approximately 57% were from rural Alabama, and approximately 42% had lower than a high school diploma-level education (Table 1). CanCORS participants were more likely to be women (66.7% *v* 50%) and age > 75 years (37.5% *v* 27.8%) and less likely to have stage III disease (25% *v* 47.2%) compared with ASCR participants²² (data not shown). Overall, 31 participants (52%) were classified as compliant with surveillance guidelines (Table 1). Noncompliant respondents were older than compliant respondents ($P = .09$).

Most respondents (compliant, 80.6%; noncompliant, 75.9%) recalled receiving some instructions about surveillance ($P = .65$; Fig 1). Instructions about timing and frequency of follow-up visits varied even among survivors with the same disease stage; frequency recommendations ranged from every month to every year for physician visits and from every 1 to 3 years for colonoscopy (Table 2). Several respondents recalled having had a colonoscopy every year since the end of treatment. Some participants reported that their physicians took care to stress the importance of surveillance: "He told me that it was very important that I keep my appointments and that I follow-up with him"; "They really explained it to me, and I was having the tests done for my own benefit." Others reported that instructions received were vague or lacked detail: "Yeah, the instructions wasn't much. Get in to see your doctor, have the colonoscopy exam"; "He suggested that I do a follow-up." Only one respondent potentially recalled being given a treatment summary: "I think he gave me some papers, what was wrong and what the procedure was and everything."

Most participants (compliant, 87.1%; noncompliant, 79.3%; $P = .50$) understood the importance of follow-up care, its purpose, and the procedures (Fig 1), namely that surveillance was important to "watch for polyps and the return of cancer" and even the spread of cancer (Table 2). Most participants across groups expressed that surveillance was important to catch a recurrence early when they could still do something about it (Table 2). At the same time, some participants expressed that

Table 1. Demographic and Clinical Characteristics of 60 African American CRC Survivors

Characteristic	% of Participants			P
	All (N = 60)	Compliant (n = 31)	Noncompliant (n = 29)	
Recruitment				.46
Deep South CanCORS site	40.0	35.5	44.8	
Alabama Statewide Cancer Registry	60.0	64.5	55.2	
Sex				.82
Male	43.3	41.9	44.8	
Female	56.7	58.1	55.2	
Age, years				.09
40-64	40.0	48.4	31.0	
65-74	28.3	16.1	41.4	
≥ 75	31.7	35.5	27.6	
Disease stage				.47
I	30.0	29.0	31.0	
II	31.7	25.8	37.9	
III	38.3	45.2	31.0	
Location				.45
Urban	43.3	38.7	48.3	
Rural	56.7	61.3	51.7	
Education level				.74
< 12 years of school	41.7	38.7	44.8	
12 years of school	28.3	25.8	31.0	
Vocational, business, or trade school	11.7	16.1	6.9	
At least some college	18.3	19.3	17.2	

Abbreviations: CanCORS, Cancer Care and Outcomes Research and Surveillance; CRC, colorectal cancer.

they did not recall the follow-up protocol or did not know which tests to get, and some did not seem interested in surveillance, especially when probed about whether they knew what tests to have to remain cancer free. Approximately 42% lacked knowledge of or interest in surveillance; for example, participants expressed that they really did not know which tests to get (Table 2). However, participants reported relying on physicians to tell them what and when they needed to return for their visits or procedures (Table 2). Noncompliant respondents (51.7%) were more likely than compliant respondents (32.3%) to express lack of knowledge or interest in surveillance ($P = .13$; Fig 1).

The interviews also highlighted other potential differences between compliant and noncompliant survivors. Only approximately 19% of compliant and almost 38% of noncompliant survivors indicated they discovered CRC through a routine visit or screening ($P = .11$). Compliant survivors may have been more likely to receive chemotherapy (compliant, 71%; noncompliant, 55.2%; $P = .20$), more likely to mention interactions with a primary care physician during and/or after CRC treatment (compliant, 71%; noncompliant, 48.3%; $P = .07$), and more likely to indicate that they were not told they were cancer free after their treatment or were told they would be

Figure 1. Frequency of selected themes from in-depth interviews with Y So Low participants (60 African American colorectal cancer survivors).

considered cancer free only after 5 years of disease-free surveillance (compliant, 32.3%; noncompliant, 13.8%; $P = .09$). Overall, most participants stated they were satisfied with the care they received, and there were no differences in the proportion of participants reporting barriers to accessing care. At the time of the interview, compliant survivors (74.2%) were significantly more likely than their counterparts (41.4%) to describe quality-of-life limitation (ie, to indicate some limitations in everyday activities, whether they resulted from age or medical comorbidities; $P = .01$).

Discussion

The uptake of surveillance after CRC treatment remains a concern, with only approximately 50% of CRC survivors receiving timely recommended colon examinations^{6,7,21} and African Americans lagging behind white survivors.^{8,9,11,22} We conducted in-depth interviews with African American CRC survivors to understand factors that may lead them to or prevent them from adhering to surveillance guidelines. Although several themes emerged from the interviews, the scope of this article was to report on what CRC survivors knew and understood about surveillance. Most of the interviewees understood why surveillance was necessary, were determined to catch recurrences early, and did not have significant barriers to accessing health care. However, not all were compliant with surveillance guidelines. Noncompliant survivors were less likely to clearly understand what to do to remain cancer free and, instead, relied on physicians directing them on what to do. However, directions from physicians and communication of the importance of surveillance, as recalled by the interviewees, were varied and inconsistent. It is, thus, important to understand whether physicians appropriately communicate national guidelines to CRC survivors and whether survivors understand these communications. Moreover, compliant and noncompliant survivors de-

Table 2. Selected Interview Quotes From African American CRC Survivors

Theme	Compliant	Noncompliant
Post-treatment instruction received		
Stage I	"He needed to schedule me for a colonoscopy once a year, and I've been doing that for 5 years." "Dr XXXX told me that he removed everything, and there was no trace of cancer and that I would have to come back and do a colonoscopy every year."	"He just told me to make sure I call and make an appointment once a year for another colonoscopy to make sure I continue to be cancer free."
Stage II	"Just get regular checkups and colonoscopy at least once a year." "Make sure I did the follow-ups. Normally, you come back in a year and get the tests done, and if everything is okay, then you come back in 2 years and if everything is okay after that, then the next time would be 5 years. If nothing has happened after that, then you're cancer free."	"Yeah, well, mostly the thing they told me, like the colonoscopy, I had that every 2 years. He told me that, and the CT scan." "Yeah, right, right, right. I was told that I would have a colonoscopy, I think, every 3 years. I've had one or two since then."
Stage III	"She told me that I needed to have CT scans every 3 months that it was very, very important." "He suggested that I do a follow-up, which I've been doing every 6 months. . . . I've been having my colonoscopy every year since that time."	"Come back every 3 months and get my blood tests to see what was going on." "He told me I would be coming back every year to take a CT scan, take blood work." "It was a colonoscopy taken every 2 years, I believe it was."
Understanding of follow-up	"To watch for polyps and the return of cancer and the spread of cancer in other organs." "That's the reason I stays up with my follow-up because, like I said, I wouldn't like one to just pop up on me, and I wouldn't know nothing about it."	"That's the purpose of going and taking the follow-up, doing the follow-up, you know, to make sure that it does not return, and if it does, you can get it before it gets too far advanced." "The doctor, the nurse, you know, I mean, she'd be in the room, but Dr XXXX always explained the importance of getting my colonoscopy and lab work, and as he put it, we're trying to do preventive medicine to make sure that it won't happen again."
Lack of knowledge of/interest in surveillance	"No, I didn't. I didn't know what I needed to do, except go to Dr XXXX when it was time and go to the lab, and they take all that blood out of you, and then go to him after that to get the report." "No, they ain't told me nothing but told me Dr XXXX would tell me when to come back to the lab."	"I don't know exactly what tests to take to stay cancer free, but I figure the doctor would tell me which ones."

Abbreviations: CRC, colorectal cancer; CT, computed tomography.

scribed different cancer experiences (ie, differences in how they found out about having CRC, treatment they received, physicians from whom they received care, messages they received after surgery and treatment, and quality of life). These findings suggest that compliant and noncompliant survivors may have different attitudes toward obtaining surveillance and different reasons or ways of interacting with the health care system.

The reasons why participants recalled inconsistent physician recommendations are not clear. This may, in part, reflect physicians' understanding of inconsistent evidence disseminated over time on the efficacy of surveillance with regard to survival, detection of recurrences, and detection of recurrences at a curative stage.^{1,23-26} Moreover, guidelines may not provide consistent recommendations for the timing and intensity of follow-up, possibly leaving a busy physician uncertain on what directions to give to patients. The existence of unclear guidelines was one of the barriers identified by oncologists to providing adequate follow-up.¹⁴ Not all physicians follow guidelines¹⁵ or are confident of following standard guidelines.¹⁶ Furthermore, as other studies have shown,^{9,11,27,28} Y So Low participants with higher-stage disease were more likely to be compliant with surveillance. Reasons may again have been related to inconsistent recommendations, with more timely and frequent follow-up recommended to survivors with more advanced disease than to those with early-stage malignancies.

Consensus guidelines, better education of physicians, decision support systems, or other system-level interventions to reduce uncertainty and provide more guidance to busy physicians are warranted to assure better surveillance uptake for all CRC survivors at any stage of disease. This is especially important, considering participants assumed that the physician would tell them what to do, even if they themselves did not clearly understand the surveillance process. Alternatively, the inconsistent recall of physicians' recommendations may reflect variation in patient understanding and/or processing of surveillance information. Conceivably, physicians may have provided clear and complete information, but survivors, especially those who were noncompliant, may have had a limited understanding of the instructions. It is important to consider, for example, that low health literacy affects what patients recall of verbal or written medical instructions.²⁹⁻³² Research should further investigate health literacy and other factors that affect the recall and understanding of directions about surveillance, and if indicated, physicians should be trained to communicate with survivors effectively.

Our results are comparable to those seen by others investigating surveillance behaviors of CRC survivors of different racial and ethnic groups. For example, in one study, patients strongly agreed that follow-up was important to improve chances of survival.¹⁴ Similarly, most of our participants knew and thought it was desirable to undergo follow-up to find re-

currences early. Among white and minority participants at the North Carolina CanCORS site, the perceived likelihood of CRC returning was a strong predictor of the intention to obtain another colonoscopy within 5 years of diagnosis, whereas physician recommendation was not.³³ These results somewhat agree with our finding that most of our participants, compliant and noncompliant, received physician instructions for follow-up; thus, having this recommendation was not associated with being compliant. However, noncompliant survivors were less clear on what follow-up tests to have. Similarly, among African American and African breast cancer survivors, lack of information about follow-up care acted as a barrier to obtaining surveillance mammograms.¹³ Thus, providing clear information about surveillance is fundamental.

It is also important to understand how the overall cancer experience relates to surveillance-seeking behavior. Compliant survivors lived a more intense cancer experience; they were more likely not to have been told that they were cancer free after their initial treatment, more likely to have received chemotherapy, and more likely to report quality-of-life limitations at the time of the interview. Noncompliant survivors, instead, were probably more likely to be diagnosed through a routine visit or screening; only a few reported not being told they were cancer free after treatment, and fewer reported quality-of-life limitations. This is in line with previous reports in which compliant survivors were more likely to have had advanced-stage disease and have received chemotherapy.^{9,11,27,28} However, contrary to our findings, a previous study found that undergoing a colonoscopy in the year before diagnosis or surgery was associated with compliance rather than noncompliance.²⁷ Therefore, further investigation is warranted into how the attitudes of survivors toward surveillance, or the perceived need for surveillance, vary depending on the cancer detection and treatment experience and on survivors' quality of life. More research is also warranted to understand the effect that messages such as "you are not cancer free yet" or "all the tumor has been taken out" may have on a survivor's perception of the importance of undergoing surveillance.

This study has limitations. Screening surveys and in-depth interviews were conducted several years after diagnosis, and the recall of instructions received after treatment may have been compromised. Reported compliance with surveillance guidelines was based on respondents' recall of procedures received and was not confirmed with medical records. We do not know how accurately survivors recalled the use of such procedures. However, the validity of recalling screening colonoscopy is acceptable,³⁴⁻³⁷ and concordance of recalled screening tests, especially colonoscopy, with medical records is not different between whites and African Americans.³⁷ Thus, self-report of surveillance procedures may be similarly valid. The number of participants we interviewed was small, and this may be the reason why differences between compliant and noncompliant survivors were not significant at a lower α . However, 60 is an adequate number of participants for a qualitative study, and saturation was reached. Moreover, participants were from Alabama only; therefore, generalizability of findings to CRC survivors in other parts of the United States is limited. However, a

large part of the African American population lives in the southeastern United States; thus, our participants may represent African Americans in this region. Finally, several other themes related to survivors' cultural beliefs, faith, and support from family, faith communities, and other survivors emerged from the interviews and may explain differences between compliant and noncompliant survivors.

In summary, *Y So Low* is the first study to our knowledge to explore in-depth reasons why African American CRC survivors may not undergo the surveillance they need after CRC treatment. With this article, we highlight the need to investigate discrepancies between physician communications and patient recall and comprehension of the messages received. Providers need to communicate clearly the importance of and expectations for surveillance to all patients with CRC regardless of stage of disease or treatment course. Investigations about what is communicated to patients after primary treatment, and how it is communicated, are also warranted. The message should reassure patients about the success of therapy, while at the same time stressing the importance of follow-up for a number of years after that treatment has ended. Moreover, it is important to assess the need for better provider education about surveillance, for systems that facilitate guideline-consistent directions to be given to patients, and for programs that enhance patient-provider communication. Most importantly, providers should ensure that patients understand the importance of being compliant with CRC surveillance.

Acknowledgment

Supported by Grants No. MM-1129 09/09 from the Centers for Disease Control and Prevention/Association of American Medical Colleges; No. U01 CA93324, U01 CA93326, U01 CA93329, U01 CA93332, U01 CA93339, U01 CA93344, and U01 CA93348 from the National Cancer Institute; and No. CRS 02-164 from the Department of Veterans Affairs for Cancer Care and Outcomes Research and Surveillance. Presented at the Ninth Annual Conference of the American Psychosocial Oncology Society, Miami, FL, February 23-25, 2012. The findings and conclusions are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention. We thank the Alabama Statewide Cancer Registry and Patricia Harris, Arlene Pettaway, Robert Smith, James Anderson, Eddie Lue Wilson, Clar-etta Warren, and another anonymous participant for their invaluable contribution as the patient advisory panel.

Authors' Disclosures of Potential Conflicts of Interest

Although all authors completed the disclosure declaration, the following author(s) and/or an author's immediate family member(s) indicated a financial or other interest that is relevant to the subject matter under consideration in this article. Certain relationships marked with a "U" are those for which no compensation was received; those relationships marked with a "C" were compensated. For a detailed description of the disclosure categories, or for more information about ASCO's conflict of interest policy, please refer to the Author Disclosure Declaration and the Disclosures of Potential Conflicts of Interest section in Information for Contributors.

Employment or Leadership Position: None **Consultant or Advisory Role:** None **Stock Ownership:** None **Honoraria:** None **Research Funding:** Maria Pisu, Centers for Disease Control and Prevention, National Institutes of Health; Robert A. Oster, Centers for Disease Control and Prevention/Association of American Medical Colleges, National Cancer Institute, Veterans Administration **Expert Testimony:** None **Patents, Royalties, and Licenses:** None **Other Remuneration:** None

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Final approval of manuscript: All authors

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DOI: 10.1200/JOP.2013.001203; published online ahead of print at jop.ascpubs.org January 2, 2014.