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Patients' Information Needs and Attitudes About Post-treatment Surveillance for Colorectal Cancer: A Multi-Perspective, Mixed Methods Study

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Running heading: Patient's Surveillance Education Needs

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ABSTRACT

Objective: To determine patients' informational needs for post-treatment surveillance. Then determine what clinicians and patient advocates feel patients should know about post-treatment surveillance.

Design: A mixed-methods study, using semi-structured interviews followed by a survey study.

Setting: Participants for the interviews were from two large academic medical centers and a safety-net hospital. The clinicians and patient advocates were recruited from attendees at the Alliance for Clinical Trials in Oncology Network Spring 2016 meeting.

Participants: Participants for the in-depth interviews were purposively sampled. Eligible patients included those who were 6-months to 5-years post curative resection for colorectal cancer and were fluent in English. Participants for the anonymous survey included clinicians and patient advocates.

Main Outcome(s) and Measure(s): The main outcome was patients with colorectal cancer informational needs for post-treatment surveillance, using an interview guide. The second outcome was the importance of the identified informational needs using an anonymous survey.

Results: Of the 31 patients interviewed, the majority were between 1- to 3-years post-treatment (81%) and diagnosed at stage III (74%). Despite a desire to monitor for cancer recurrence, patients had little understanding of the concept of post-treatment surveillance, equating surveillance with screening and a belief that if a recurrence was found early there would be a higher likelihood of cure. The survey suggested that clinicians (n=38) and patient advocates (n=11) had some differing opinions regarding what patients should know about surveillance to be active in decisions. For example, patient advocates felt that patients should know recurrence treatment options (100% vs 58%) and likelihood for cure following recurrence treatment (100% vs 38%).

Conclusions: The results of this mixed-methods study indicate that novel educational interventions targeting both clinicians and patients are needed to address the mismatch across perspectives and misunderstanding of surveillance.

Keywords: Colorectal cancer, medical oncology clinical decision making, patient preference, health services research

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STRENGTHS AND LIMITATION OF THIS STUDY

- Patients were recruited from multiple clinical settings, representing patients from different socioeconomic backgrounds.
- One of the few studies to examine patients' informational needs following curative treatment for colorectal cancer, surveillance.
- We used convenience sampling of attendees at a single meeting for the survey portion of the study.

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1 BACKGROUND

Colorectal cancer (CRC) is the third leading cancer in men and women and the fourth most common cancer overall [1, 2]. Nearly 80% of all newly diagnosed CRC patients will be eligible for curative resection followed by post-treatment surveillance to detect recurrence and manage treatment associated effects [3]. Among those patients who develop recurrence, approximately 1 in 3 to 4 patients will be eligible for salvage surgery with curative intent [4-6]. Salvage surgery is associated with long-term survival of 30-50%. However, not all patients will develop recurrence or be eligible for salvage resection, and it is estimated that between 15 and 50 patients undergo repeated surveillance testing to identify one patient eligible for salvage surgery.

Current guidelines for the frequency or duration of surveillance evaluation are variable, and there is uncertainty regarding the optimal timing, frequency, duration, and modality of surveillance monitoring that should be conducted and for whom [7]. As a result, it is imperative that patients are active in their care and knowledgeable about CRC post-treatment surveillance and recurrence.

Prior studies have shown that CRC survivors who have had curative resection for CRC have limited knowledge about surveillance testing and risks for recurrence [8]. However, these previous studies provide limited guidance about identifying different key facts survivors need to understand so they can be active participants in decision making about CRC post-treatment surveillance planning or recurrence treatment. The purpose of this study was to explore the views of clinicians and patient advocates about the necessary information patients should have to promote active participation in decisions about post-treatment surveillance, and to determine CRC patients' knowledge regarding post-treatment surveillance.

2 METHODS

2.1 Study Design

This was a mixed-methods study consisting of semi-structured, in-depth interviews with patients and a survey with clinicians and patient advocates. This study was approved by The University of Texas MD Anderson Cancer Center Institutional Review Board.

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2.2. Patient and Public Involvement

Patient advocates and stakeholders from the Alliance for Clinical Trials in Oncology were involved in all aspects of the study from development of the research question, outcome measures, study design, and data collection strategies during our biannual meetings. We presented the results to the stakeholders at an in-person meeting. Results were not shared with patient participants.

2.3 Study Procedures

2.3.1 Patients: Patients were recruited from two large academic cancer centers and one safety-net hospital. Eligible patients were 6-months to 5-years from curative resection of their colon or rectum and were fluent in English. Researchers with no prior relationship with potential participants reviewed the upcoming surveillance appointments to identify eligible patients and assess interest in participating. After consent, the interviews were conducted either by phone or in-person by a male (VFR) with over 5-years of research experience with a Bachelors degree or a female (APH) research assistant with 2-3 years of research experience with a Bachelors degree. Both were trained by the first author to conduct the interviews. Interview participants knew the interviewers name and the purpose of the study. All interviews lasted about an hour and were audio-recorded and transcribed verbatim. Transcripts were not returned to the participants for comment and/or corrections.

2.3.2 Clinicians and Patient Advocates (Stakeholders): Stakeholders who attended the Spring 2016 meeting of the Alliance for Clinical Trials in Oncology Network were eligible to participate. The stakeholders included gastrointestinal clinicians from academic and non-academic community-based practices and patient advocates.

2.4 Data Collection Instruments and Analysis

***2.4.1 Semi-structured interview guide and analysis*:** The semi-structured interview guide was developed by review of the literature and expert opinion and was iteratively refined during the data collection period. The final guide is available by request.

Framework method guided the thematic analysis [9]. Two or more researchers (LML, AC, GJC) coded all transcripts and met to discuss the coded transcripts. The coded texts were labeled with both deductive and inductive

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codes. The deductive codes were derived from the interview guide, and the inductive codes were developed iteratively. The coded texts were grouped together into themes and sub-themes to describe the range of patient knowledge and attitudes regarding CRC surveillance. The coded text were rated on a dichotomous scale or a Likert scale ranging from low knowledge to high knowledge (Table 1).

The analysis also included comparing the themes and sub-themes across groups, such as comparing patients who were high versus low risk for recurrence based upon stage of diagnosis and comparing patients from the different recruitment sites. Atlas.ti version 7 was used to facilitate analysis of the coded transcripts.

2.4.2 Stakeholder survey: Using the data from the qualitative interviews, we developed an anonymous survey to determine what clinicians and patient advocates think is important for patients to know to make decisions about post-treatment surveillance. Additionally, candidate items were initially taken from published guidelines and expert opinion. The candidate list was reviewed by LML, AC, and GJC for clarity, redundancy, and importance to determine the necessary facts and key messages to include in the survey. The survey asked the clinicians and patient advocates to indicate whether a fact or key message was necessary to make an informed decision about CRC surveillance by selecting agree, neutral, or disagree. All survey data was collected anonymously. Analysis of the stakeholder surveys included counts and proportions.

3 RESULTS

3.1 Description of stakeholders and patients

A total of 32 patients were interviewed from the three different medical centers, and 38 clinicians and 11 patient advocates completed the anonymous survey (Table 2). One patient was not included in the analysis because of a diagnosis of Lynch Syndrome. More than half of the patients were male (61%), and the majority were White (71%), non-Hispanic (90%), and married (71%). There was a good representation of educational levels with slightly more than half of individuals with less than a college education (52%). The majority of the patients were between 1- to 3-years post-treatment, had colon cancer, and were diagnosed at stage III.

3.2 Patients' perceptions of surveillance

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An overarching theme from the in-depth interviews was that patients had significant knowledge gaps regarding treatment, surveillance, and recurrence (Table 3). Patients generally had an accurate understanding of their stage at diagnosis (77%, 23/30) and site of cancer (85%, 22/26) based on their personal experience. However, there were patients who were confused about their stage and didn't completely grasp the difference between cancer in the colon or rectum.

> *Interviewer: It was colorectal, so was it in your rectum or what—or was it?*
>
> *Patient: Yeah, I guess. I guess you'd say that*
>
> *Interviewer: Okay. Your colon?*
>
> *Patient: They had me with a—you know—a ostomy—a colostomy bag*
>
> (Patient 31)

Overall, despite a desire to monitor for recurrence, patients had an incomplete understanding of recurrence mechanism, site, natural history, and potential for cure (Table 3). Very few patients could define cancer recurrence or describe where and when recurrence was most likely to occur. They described recurrence as "*cancer coming back - Patient 03*" and a minority of patients could state that recurrence was most likely to occur in the lungs or liver. Few understood the limited potential for cure after recurrence, which was demonstrated by the belief that the treatment for recurrence would be the same as the treatment for the primary cancer: "*I think pretty much probably the same, chemo and surgery, maybe radiation – Patient 04*". Many confused recurrence with a new primary colon cancer (*"Because you can have cancer further up" – Patient 05*). Patients commonly believed that if recurrence was found early, there was a higher likelihood for cure; this concept may have been influenced by broader concepts of CRC screening and early detection of primary disease. For instance, one patient's description of the purpose of surveillance demonstrates the inability to differentiate screening and early detection of primary disease and surveillance for detection of recurrence, which is compounded by the belief that recurrence of cancer can be prevented. *"To make sure […] that nothing has changed in the body […] this time they found polyps […] It's also preventative. – Patient 05"*

Patients had little understanding of the concept of post-treatment surveillance (Table 3). They were able to broadly list the tests involved and general frequency of these tests, but it was from their experience and not from a deeper understanding of the reasons for the tests or the rationale for testing frequency or duration. Additionally, patients did

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not seem to think there were specific harms to surveillance testing, or they mentioned harms in passing. For example, one patient mentioned radiation as a possible harm but of minimal concern. Concern for false positive test results and possible need for additional testing also did not arise.

Patients equated the term surveillance with "follow-up," but in general lacked a granular understanding of the purpose of surveillance and its implications for survival. However, one patient differentiated between "surveillance" and "follow-up." For this patient, "surveillance" was clearly about detecting recurrence: *"Okay. So, in my mind, surveillance is looking for a recurrence or a metastasis. Like the scans I consider surveillance. The CEA level I consider surveillance. The colonoscopy and the sigmoidoscopy I consider surveillance. – Patient 21"*

The concept of "follow-up" was about maintaining quality of life:

> *"And then follow-up care—I mean since I had my ileostomy reversal in [date]—I mean I'm not sure how familiar you are with—you know—kind of how that goes and what the healing is like, but I feel like it was a really long haul and it's been almost more difficult than having chemo. It's kind of getting back to like regular bowel function. So, I was seeing—and this is where I've gotten my just kind of follow-up care that's not surveillance, but I had visits with a nutritionist I had visits with another nurse in my surgeon's practice. I had visits with a pelvic floor physical therapist. – Patient 21"*

Although some patients stated they were going to be followed for 5 years, they had little to no understanding of the rationale for the follow-up time window. For those who were not able to express the 5 year duration, they expressed a belief that they would always be followed. For example one patient said "*I always expect to be — you know— checked up on once in a while. You know? Just to make sure it didn't come back. – Patient 06*"

3.3 Stakeholder opinions regarding information patients should know about CRC surveillance

Advocates and clinicians agreed that slightly half of the topics (6 out of 13 topics) were important for patients to know: duration and frequency of surveillance, tests used for surveillance, the purpose of surveillance, timing of recurrence, definition of recurrence, and basic CRC facts (Fig. 1). There was disagreement on four of these topics.

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Advocates felt that patients should know site of recurrence (90% vs 65%), the treatment options for recurrence (100% vs 58%), goals of treatment (e.g., curative or palliative) for recurrence (100% vs 38%), and potential harms of surveillance testing (100% vs 68%). Compared to clinicians, somewhat fewer advocates felt that patients should know the impact of surveillance on survival (55% vs 70%) and situations where surveillance may not be beneficial, such as advanced age (55% vs 76%).

DISCUSSION

This study highlights areas for consideration regarding what stakeholders believe patients should know in order to make informed choices for their care and what patients understand about surveillance and recurrence. The in-depth interviews with patients demonstrated a good understanding of their diagnosis and treatment, but significant knowledge gaps regarding recurrence and the purpose of post-treatment surveillance. The stakeholder survey showed that patient advocates and clinicians differed in their perceptions of what patients should know about surveillance and recurrence.

Patients' misperceptions about surveillance and recurrence is an important barrier for active participation in their care [15]. The in-depth interviews demonstrated that patients do not have sufficient knowledge to actively participate in their post-treatment care; however, they did have a broad understanding of their diagnosis and treatment. Salz and colleagues found that most CRC survivors remembered information about their treatment, but had a poor grasp on their risk of local recurrence, distant recurrence, or developing a new primary CRC [8]. In our study, we found that patients did not understand the purpose of the different surveillance tests, the underlying rationale for the different timing of tests, the duration of surveillance, the natural history of recurrence, and the likelihood of cure for recurrence. Our findings are similar to those of a study conducted with African American CRC survivors, which revealed poor understanding of post-treatment surveillance testing and uncertainty about when they would be considered cured or no longer at significant risk for recurrence [16]. Thus, clinicians need effective strategies to better educate patients about CRC surveillance.

Patients' misunderstanding of CRC surveillance could be problematic for clinicians as well. Fear of recurrence is one of the most important concerns among cancer survivors [17]. They can experience significant anxiety about the

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risk for recurrence, which can be out of proportion to their actual risk and look to their clinicians to alleviate this anxiety, often with the expectation of evaluating their cancer status with a test. Clinicians may have a difficult time explaining to patients the indications and limitations of testing, the appropriate frequency, or why their visits are becoming less frequent and will eventually end after five years, especially for patients who have a high fear of recurrence and are hesitant to separate from their oncology clinicians [12]. In the event of recurrence, providers will have to explain to patients that treatment for recurrence is likely to be more difficult. However, this reality could influence patients' underlying desire for testing. These very difficult and potentially time-consuming conversations require communication of difficult concepts with careful attention to use of plain language [18].

From our stakeholder surveys, there was disagreement between patient advocates and clinicians regarding what facts or key messages need to be discussed. Our results confirm prior reports of a disconnect between patients and clinicians and highlight the importance of patient-centered care [10-12]. Since not all patients who are identified with cancer recurrence will be eligible for curative-intent treatment, the role of intensive surveillance testing in such patients can be debated. However, compared to clinicians, fewer advocates felt that patients should know about contraindications to surveillance, or the potential for limited impact of surveillance on survival. These findings may reflect a belief that everyone has the right to receipt of care, even when treatment may not be beneficial, and that patients must continue to fight cancer by monitoring its recurrence. The data may also underpin patients' unwillingness to consider situations of medical futility in patients who might be too frail to undergo salvage surgery. Far fewer clinicians felt that patients should know the potential harms of surveillance tests, recurrence treatment outcomes, potential treatments for recurrence, sites where recurrence could occur, and risk of recurrence. These results may suggest that clinicians are hesitant to get into specifics about recurrence, preferring to focus on the patient being "cancer free" for now. This idea is consistent with the results of a study analyzing patients and clinicians for post-treatment surveillance of pancreatic cancer, a disease where few options exist for treatment should recurrence be identified [12]. It could also reflect clinicians' difficulty with providing individualized information on prognosis while still providing hope [13, 14].

A limitation of this study is the small sample size; however, thematic saturation was reached within 10 to 15 interviews regarding patients' expressed knowledge and new thematic insights are unlikely to be achieved simply by

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interviewing more patients. The sample was also diverse with respect to education level and included patients from a safety-net hospital. The results of the stakeholder surveys warrants further exploration with larger and more diverse sample sizes for both patient advocates and clinicians. The patient advocates may not represent patients at large as they are more engaged and knowledgeable about post-treatment surveillance for cancer. The clinicians represented practicing academic and community clinicians.

In summary, patients have a significant knowledge gap regarding post-treatment surveillance and recurrence. There is a strong belief among patient advocates that clinicians should attempt to help their patients to be more informed about their disease and associated treatments. Patients need educational interventions to address these gaps to be more active in their care. Clinicians would also benefit from interventions to promote conversations about post-treatment surveillance of CRC that more closely align with the information needs of patients. One promising approach is educational interventions combined with communication skills training for providers. Such interventions could help patients and clinicians be clear about the goals of care during post-treatment surveillance and recurrence, resulting in more patient-centered care.

CONTRIBUTORS

LML contributed to the conceptualization and design, collection and assembly of data, data analysis and interpretation, manuscript writing, and final approval of manuscript. RJV contributed to the conceptualization and design, data interpretation, manuscript writing, and final approval of manuscript. AC contributed to the collection of data, data analysis and interpretation, manuscript writing, and final approval. APH contributed to data collection and interpretation, manuscript editing, and final approval of manuscript. YNY, KVL, SM, JAM, and PG contributed to data interpretation, manuscript writing, and final approval of manuscript. GJC contributed to the conceptualization and design, data analysis and interpretation, manuscript writing, and final approval of manuscript.

DATA SHARING STATEMENT

Data are available from the principal investigator, George J. Chang, on request.

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CONFLICTS OF INTEREST

All authors have no conflicts of interest to report associated with this article.

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Fig. 1 Comparing stakeholder responses

This figure presents the stakeholder responses to what they feel patients should know about surveillance following curative resection of their colon or rectum. The values presented are in percentages. Abbreviations: GI, gastrointestinal.

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Table 1. Patient Knowledge Coding Framework

Code	Definition
Stage of diagnosis	• No: Does not accurately state the stage of diagnosis. • Yes: Able to accurately state the stage of diagnosis.
Site of diagnosis	• No: Does not accurately state the site of diagnosis. • Yes: Able to accurately state the site of diagnosis.
How the cancer was detected	• No: Unable to express how his or her cancer was detected. • Yes: Able to express how his or her cancer was detected.
Treatment modality and sequence	• Low: Does not accurately describe or provide any details about how the cancer was detected. • Medium: Provides more detail regarding treatments such as sequence and type of surgery or doses of chemotherapy. • High: Provides correct facts about modality and sequence, uses the correct terms for treatment regimen (e.g., can name the chemotherapy).
Surveillance tests (e.g., CEA, endoscopy, colonoscopy, imaging)	• Low: Does not name the tests or names one test. • Medium: Can list some tests (2/4). • High: Knows most of the tests (3/4) or why they were being done.
Harms of surveillance testing	• Low: Is not able to list any harms of testing. • Medium: Knows that risks exist but cannot explain or has poor understanding of the implications. • High: Has realistic understanding/quantification of harms. (ex. Radiation exposure secondary cancer risk, but it is very low; false positives as a risk of over-surveillance)
Frequency of surveillance tests	• Low: Has no idea. • Medium: Has some idea of testing frequency but is not communicated clearly/correctly. • High: Differentiates the different timing between the tests.
Duration of follow-up	• Low: Has no idea. • Medium: Has some concept of duration. • High: Understands and can communicate duration; makes reference to appropriate timeline (ex. 5 years).
Purpose of surveillance	• Low: Unable to express the rationale for testing. • Medium: Able to express to make sure cancer is not coming back. • High: States that surveillance is to monitor for recurrence and toxicity for long-term effects, references quality of life, or life planning.
Site of recurrence	• Low: Believes that recurrence will be more likely to come back in the colon or has no idea where recurrence will occur. • Medium: Believes that recurrence will occur somewhere other than the colon. • High: Differentiates between distant and local recurrence, and/or able to describe that recurrence will likely occur in the liver or lungs.
Sense of risk for recurrence	• Low: Cannot describe or unsure of his or her risk for recurrence. • Medium: Has a general sense of risk but lacks detail. • High: Appropriately characterizes his or her risk (e.g., risk of recurrence can be different for people; distant is higher risk than local; earlier in post-treatment surveillance the risk is higher).

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Table 1. Patient Knowledge Coding Framework

Code	Definition
Natural history of recurrence	• Low: Does not understand how recurrence develops. • Medium: Has a broad understanding of recurrence development. • High: Shows understanding of recurrence development.
Treatment options for recurrence	• Low: Is unable to describe or believes treatment for recurrence will be easy and straightforward or like what they had initially. • Medium: Mentions some options for treatment of recurrence and/or states that treatment will be different from the treatment for their primary CRC. • High: Understands that treatment will be difficult.
Likelihood of cure	• Low: Believes the likelihood of cure is high or has no idea. • Medium: Knows that it may be harder to cure but lacks complete understanding. • High: Knows that recurrence is very difficult to cure.

Abbreviations: CEA, carcinoembrionic antigen; CRC, colorectal cancer.

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Table 2. Patient Characteristics (n=31)

	n (%)
Age (median, IQR)	60 (53-68)
Gender	
Male	19 (61.3)
Female	12 (38.7)
Race	
White	22 (71.0)
Black	5 (16.1)
Other	4 (12.9)
Ethnicity	
Non-Hispanic	28 (90.3)
Hispanic	3 (9.7)
Education	
High school or less	10 (32.3)
Some college/vocational training	6 (19.4)
College	10 (32.3)
Advanced degree	5 (16.1)
Marital status	
Married	22 (71.0)
Not married	9 (29.0)
Time from surgery (months)	
6-12	5 (16.1)
13-36	20 (64.5)
37-48	6 (19.4)
Tumor site	
Colon	21 (67.7)
Rectum	10 (32.3)
Stage at diagnosis	
Stage I	3 (9.7)
Stage II	5 (16.1)
Stage III	23 (74.2)

Abbreviations: IQR, interquartile range.

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Table 3. Patient Knowledge of Post-treatment Colorectal Cancer Surveillance and Recurrence

	Mentioned n (%)	Quality of expressed knowledge[a]		
		Low n (%)	Medium n (%)	High n (%)
Treatment modality and sequence	31 (100.0)	1 (3.2)	23 (74.2)	7 (22.6)
Types of surveillance tests	30 (96.8)	5 (16.7)	14 (46.7)	11 (36.7)
Frequency of surveillance tests	31(100.0)	8 (25.9)	21 (67.7)	2 (6.5)
Harms of surveillance testing	21 (67.7)	9 (29.0)	11 (52.4)	1 (4.8)
Duration of surveillance	24 (77.4)	10 (41.7)	7 (29.2)	7 (29.2)
Purpose of surveillance	31 (100.0)	5 (16.1)	20 (64.5)	6 (19.4)
Site of recurrence	27 (87.1)	20 (74.1)	4 (14.8)	3 (11.1)
Sense of risk for recurrence	24 (77.4)	16 (66.7)	5 (20.1)	3 (12.5)
Natural history of recurrence	19 (61.3)	14 (73.1)	4 (21.1)	1 (5.3)
Treatment options for recurrence	26 (83.9)	21 (80.1)	5 (19.2)	0 (0.0)
Likelihood of cure	24 (77.4)	15 (62.5)	8 (33.3)	1 (4.2)

[a]The quality of expressed knowledge is based upon the denominator of those mentioning the knowledge element.

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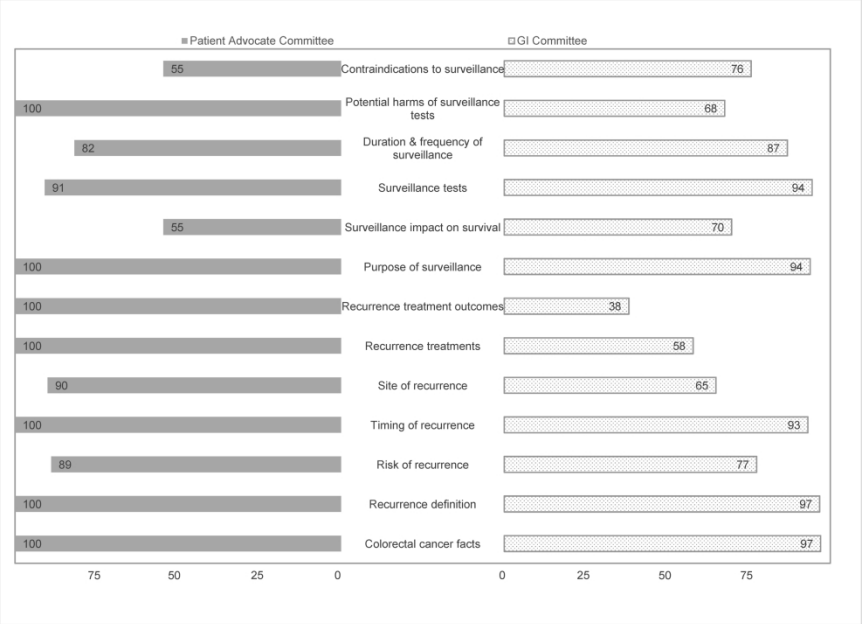

Fig. 1 Comparing stakeholder responses
This figure presents the stakeholder responses to what they feel patients should know about surveillance following curative resection of their colon or rectum. The values presented are in percentages.
Abbreviations: GI, gastrointestinal.

279x215mm (300 x 300 DPI)

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Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No	Item	Guide questions/description	Page
Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	6
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*	6
3.	Occupation	What was their occupation at the time of the study?	6
4.	Gender	Was the researcher male or female?	6
5.	Experience and training	What experience or training did the researcher have?	6
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	6
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e.*g. personal goals, reasons for doing the research*	6
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. *Bias, assumptions, reasons and interests in the research topic*	6
Domain 2: study design			
Theoretical framework			
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*	6

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No	Item	Guide questions/description	Page
Participant selection			
10.	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*	6
11.	Method of approach	How were participants approached? e.*g. face-to-face, telephone, mail, email*	6
12.	Sample size	How many participants were in the study?	7
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	Not reported
Setting			
14.	Setting of data collection	Where was the data collected? e.*g. home, clinic, workplace*	6
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	Not reported
16.	Description of sample	What are the important characteristics of the sample? *e.g. demographic data, date*	7
Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	6
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	NA
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	6
20.	Field notes	Were field notes made during and/or after the interview or focus group?	NA
21.	Duration	What was the duration of the interviews or focus group?	6

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No	Item	Guide questions/description	Page
22.	Data saturation	Was data saturation discussed?	11
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	6
Domain 3: analysis and findings			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	6
25.	Description of the coding tree	Did authors provide a description of the coding tree?	17
26.	Derivation of themes	Were themes identified in advance or derived from the data?	7
27.	Software	What software, if applicable, was used to manage the data?	7
28.	Participant checking	Did participants provide feedback on the findings?	6
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.*g. participant number*	8-9
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Yes
31.	Clarity of major themes	Were major themes clearly presented in the findings?	8-9
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	8-9

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Patients' Information Needs and Attitudes About Post-treatment Surveillance for Colorectal Cancer in the United States: A Multi-Perspective, Mixed Methods Study

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Running heading: Patient's Surveillance Education Needs

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ABSTRACT

Objective: We sought to determine patients' informational needs for post-treatment surveillance and elicit clinicians' and patient advocates' (i.e., stakeholders) opinions regarding what patients should know about post-treatment surveillance in the United States.

Design: A mixed-methods study, using semi-structured interviews followed by a survey study.

Setting: Participants for the interviews were from two large academic medical centers and a safety-net hospital. The stakeholders were recruited from attendees at the Alliance for Clinical Trials in Oncology Network Spring 2016 meeting.

Participants: Participants for the in-depth interviews were purposively sampled. Eligible patients were 6-months to 5-years post curative resection for colorectal cancer and were fluent in English. Participants for the anonymous survey were stakeholders.

Main Outcome(s) and Measure(s): The main outcome was patients' with colorectal cancer informational needs for post-treatment surveillance, using an interview guide. The second outcome was the importance of the identified informational needs using an anonymous survey.

Results: Of the 67 patients approached, 31 were interviewed (response rate = 46%), the majority were between 1- to 3-years post-treatment (81%) and diagnosed at stage III (74%). Despite a desire to monitor for cancer recurrence, patients had little understanding of the concept of post-treatment surveillance, equating surveillance with screening and a belief that if a recurrence was found early there would be a higher likelihood of cure. The survey suggested that clinicians (n=38) and patient advocates (n=11) had some differing opinions regarding what patients should know about surveillance to be active in decisions. For example, compared to clinicians, patient advocates felt that patients should know recurrence treatment options (100% vs 58%) and likelihood for cure following recurrence treatment (100% vs 38%).

Conclusions: The results of this exploratory mixed-methods study suggests that novel educational interventions targeting both patients and clinicians are needed to address the informational needs for post-treatment surveillance of colorectal cancer.

Keywords: Colorectal cancer, medical oncology clinical decision making, patient preference, health services research

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STRENGTHS AND LIMITATION OF THIS STUDY

- Patients were recruited from multiple clinical settings, representing patients from different socioeconomic backgrounds.
- One of the few studies to examine patients' informational needs following curative treatment for colorectal cancer, surveillance.
- We used convenience sampling of attendees at a single meeting for the survey portion of the study.
- The sample size for the stakeholder survey was small and exploratory in nature.

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1 BACKGROUND

Colorectal cancer (CRC) is the third leading cancer in men and women and the fourth most common cancer overall [1, 2]. Nearly 80% of all newly diagnosed patients with CRC will be eligible for curative resection followed by post-treatment surveillance to detect recurrence and manage treatment associated effects [3]. Among those patients who develop recurrence, approximately 1 in 3 to 4 patients will be eligible for salvage surgery with curative intent [4-6]. Salvage surgery is associated with long-term survival of 30-50%. However, not all patients will develop recurrence or be eligible for salvage resection, and it is estimated that between 15 and 50 patients undergo repeated surveillance testing to identify one patient eligible for salvage surgery.

Current guidelines for the frequency or duration of surveillance evaluation are variable, and there is uncertainty regarding the optimal timing, frequency, duration, and modality of surveillance monitoring that should be conducted and for whom [7]. As a result, it is imperative that patients are active in their care and knowledgeable about CRC post-treatment surveillance and recurrence.

Prior studies have shown that survivors who have had curative resection for CRC have limited knowledge about surveillance testing and risks for recurrence [8]. However, these previous studies provide limited guidance about identifying different key facts survivors should understand so they can be active participants in decision making about CRC post-treatment surveillance planning or recurrence treatment. The purpose of this study was to identify patients' with CRC informational needs and elicit clinicians' and patient advocates' opinions regarding what patients should know about post-treatment surveillance to promote active participation in decisions about post-treatment surveillance.

2 METHODS

2.1 Study Design

This was a mixed-methods study consisting of semi-structured, in-depth interviews with patients and a stakeholder survey with clinicians and patient advocates. This study was approved by The University of Texas MD Anderson Cancer Center Institutional Review Board. (Interview IRB #: PA13-1002, Stakeholder Survey IRB # PA14-0935).

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2.2. Patient and Public Involvement

Patient advocates, clinicians, and researchers from the Alliance for Clinical Trials in Oncology were involved in all aspects of the study from development of the research question, outcome measures, study design, and data collection strategies during our biannual meetings. We presented the results to the stakeholders at an in-person meeting. Results were not shared with patient participants.

2.3 Study Procedures

2.3.1 Patients: Patients were recruited from two large academic cancer centers in the West and Southwest regions and one safety-net hospital in the Southwest region of the United States. Eligible patients were ≥18 years of age, 6-months to 5-years from curative resection of their colon or rectum, and were fluent in English. Researchers with no prior relationship with potential participants reviewed the upcoming surveillance appointments to identify eligible patients and assess interest in participating. After consent, the interviews were conducted either by phone or in-person by a mail (VFR) with over 5-years of research experience with a Bachelors degree or a female (APH) research assistant with 2-3 years of research experience with a Bachelors degree. Both were trained by the first author to conduct the interviews. Interview participants knew the interviewers name and the purpose of the study. All interviews were conducted from September 2014 to July 2016, lasted about an hour, and were audio-recorded and transcribed verbatim. Transcripts were not returned to the participants for comment and/or corrections.

2.3.2 Clinicians and Patient Advocates (Stakeholders): Stakeholders who attended the Spring 2016 meeting of the Alliance for Clinical Trials in Oncology Network were eligible to participate. The stakeholders included gastrointestinal clinicians from academic and non-academic community-based practices and patient advocates. From here on out, the term “advocates” refers to “patient advocates.”

2.4 Data Collection Instruments and Analysis

***2.4.1 Semi-structured interview guide and analysis*:** The semi-structured interview guide was developed by review of the literature and expert opinion and was iteratively refined during the data collection period. The final guide is available by request.

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Framework method guided the thematic analysis [9]. Two or more researchers (LML, AC, GJC) coded all transcripts and met to discuss the coded transcripts. The coded texts were labeled with both deductive and inductive codes. The deductive codes were derived from the interview guide, and the inductive codes were developed iteratively. The coded texts were grouped together into themes and sub-themes to describe the range of patient knowledge and attitudes regarding CRC surveillance. The coded text were rated on a dichotomous scale or a Likert scale ranging from low knowledge to high knowledge (Table 1).

The analysis also included comparing the themes and sub-themes across groups, such as comparing patients who were high versus low risk for recurrence based upon stage of diagnosis and comparing patients from the different recruitment sites. Atlas.ti version 7 was used to facilitate analysis of the coded transcripts.

2.4.2 Stakeholder survey: Using the data from the qualitative interviews, we developed an anonymous survey to elicit stakeholders opinions regarding what patients should know about post-treatment surveillance. Additionally, candidate items were initially taken from published guidelines and expert opinion. The candidate list was reviewed by LML, AC, and GJC for clarity, redundancy, and importance to determine the necessary facts and key messages to include in the survey. The survey asked stakeholders to indicate whether a fact or key message was necessary to make an informed decision about CRC surveillance by selecting agree, neutral, or disagree (Supplementary File). All survey data was collected anonymously, and we did not collect demographic information from the stakeholder survey participants. Analysis of the stakeholder surveys included counts and proportions.

3 RESULTS

3.1 Description of patients and stakeholders

A total of 67 patients were contacted and 31 patients (46% response rate) were interviewed from three different medical centers (Table 2). One patient was not included in the analysis because of a diagnosis of Lynch Syndrome. More than half of the patients were male (61%), and the majority were White (71%), non-Hispanic (90%), and married (71%). There was a good representation of educational levels with slightly more than half of individuals with less than a college education (52%). The majority of the patients were between 1- to 3-years post-treatment, had colon cancer, and were diagnosed at stage III. The anonymous stakeholder survey was completed by 49

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participants (38 clinicians and 11 patient advocates). The clinicians represented practicing academic and community clinicians and the patient advocates represented individuals engaged in clinical cancer research.

3.2 Patients' knowledge of surveillance

An overarching theme from the in-depth interviews was that patients had significant knowledge gaps regarding treatment, surveillance, and recurrence (Table 3). The overarching themes were consistent regardless of education level, marital status, or time since treatment. Patients generally had an accurate understanding of their stage at diagnosis (77%, 23/30) and site of cancer (85%, 22/26) based on their personal experience. However, there were patients who were confused about their stage and didn't completely grasp the difference between cancer in the colon or rectum.

> *Interviewer: It was colorectal, so was it in your rectum or what—or was it?*
>
> *Patient: Yeah, I guess. I guess you'd say that*
>
> *Interviewer: Okay. Your colon?*
>
> *Patient: They had me with a—you know—a ostomy—a colostomy bag*
>
> (Patient 31)

Overall, despite a desire to monitor for recurrence, patients had an incomplete understanding of recurrence mechanism, site, natural history, and potential for cure (Table 3). Very few patients could define cancer recurrence or describe where and when recurrence was most likely to occur. They described recurrence as "*cancer coming back - Patient 03*" and a minority of patients could state that recurrence was most likely to occur in the lungs or liver. Few understood the limited potential for cure after recurrence, which was demonstrated by the belief that the treatment for recurrence would be the same as the treatment for the primary cancer: "*I think pretty much probably the same, chemo and surgery, maybe radiation – Patient 04*". Many confused recurrence with a new primary colon cancer (*"Because you can have cancer further up" – Patient 05*). Patients commonly believed that if recurrence was found early, there was a higher likelihood for cure; this concept may have been influenced by broader concepts of CRC screening and early detection of primary disease. For instance, one patient's description of the purpose of surveillance demonstrates the inability to differentiate screening and early detection of primary disease and surveillance for detection of recurrence, which is compounded by the belief that recurrence of cancer can be

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prevented. *"To make sure […] that nothing has changed in the body […] this time they found polyps […] It's also preventative. – Patient 05"*

Patients had little understanding of the concept of post-treatment surveillance (Table 3). They were able to broadly list the tests involved and general frequency of these tests, but it was from their experience and not from a deeper understanding of the reasons for the tests or the rationale for testing frequency or duration. Additionally, patients did not seem to think there were specific harms to surveillance testing, or they mentioned harms in passing. For example, one patient mentioned radiation as a possible harm but of minimal concern. Concern for false positive test results and possible need for additional testing also did not arise.

Patients equated the term surveillance with "follow-up," but in general lacked a granular understanding of the purpose of surveillance and its implications for survival. However, one patient differentiated between "surveillance" and "follow-up." For this patient, "surveillance" was clearly about detecting recurrence: *"Okay. So, in my mind, surveillance is looking for a recurrence or a metastasis. Like the scans I consider surveillance. The CEA level I consider surveillance. The colonoscopy and the sigmoidoscopy I consider surveillance. – Patient 21"*

The concept of "follow-up" was about maintaining quality of life:

> *"And then follow-up care—I mean since I had my ileostomy reversal in [date]—I mean I'm not sure how familiar you are with—you know—kind of how that goes and what the healing is like, but I feel like it was a really long haul and it's been almost more difficult than having chemo. It's kind of getting back to like regular bowel function. So, I was seeing—and this is where I've gotten my just kind of follow-up care that's not surveillance, but I had visits with a nutritionist I had visits with another nurse in my surgeon's practice. I had visits with a pelvic floor physical therapist. – Patient 21"*

Although some patients stated they were going to be followed for 5 years, they had little to no understanding of the rationale for the follow-up time window. For those who were not able to express the 5 year duration, they expressed a belief that they would always be followed. For example one patient said "*I always expect to be — you know— checked up on once in a while. You know? Just to make sure it didn't come back. – Patient 06*"

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3.3 Stakeholder opinions regarding information patients should know about CRC surveillance

Advocates and clinicians agreed that slightly half of the topics (6 out of 13 topics) were important for patients to know: duration and frequency of surveillance, tests used for surveillance, the purpose of surveillance, timing of recurrence, definition of recurrence, and basic CRC facts (Fig. 1). There was disagreement on four of these topics. More advocates agreed that patients should know site of recurrence (90% of advocates vs 65% of clinicians), the treatment options for recurrence (100% of advocates vs 58% of clinicians), goals of treatment (e.g., curative or palliative) for recurrence (100% of advocates vs 38% clinicians), and potential harms of surveillance testing (100% vs 68%) compared to clinicians. Compared to clinicians, somewhat fewer advocates agreed that patients should know the impact of surveillance on survival (55% of advocates vs 70% of clinicians) and situations where surveillance may not be beneficial, such as advanced age (55% of advocates vs 76% of clinicians).

DISCUSSION

This exploratory study highlights areas for consideration regarding patients' informational needs and stakeholders' opinions regarding what patients should understand about surveillance and recurrence in order to make informed choices for their care. The in-depth interviews suggested that patients understood their diagnosis and treatment, but had significant knowledge gaps regarding recurrence and the purpose of post-treatment surveillance. The stakeholder survey suggested that advocates and clinicians differed in their opinions of what patients should know about surveillance and recurrence.

Patients' misperceptions about surveillance and recurrence is an important barrier for active participation in their care [10]. The in-depth interviews suggested that patients do not have sufficient knowledge to actively participate in their post-treatment care; however, they did have a broad understanding of their diagnosis and treatment. Salz and colleagues found that most survivors of CRC remembered information about their treatment, but had a poor grasp on their risk of local recurrence, distant recurrence, or developing a new primary CRC [8]. In our study, we found that patients did not understand the purpose of the different surveillance tests, the underlying rationale for the different timing of tests, the duration of surveillance, the natural history of recurrence, and the likelihood of cure for recurrence. Our findings are similar to those of a study conducted with African American survivors of CRC, which

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revealed poor understanding of post-treatment surveillance testing and uncertainty about when they would be considered cured or no longer at significant risk for recurrence [11]. The findings from this exploratory study suggests that these knowledge gaps are present regardless of education level, marital status, and time since treatment. Thus, clinicians need effective strategies to better educate patients about CRC surveillance.

Patients' misunderstanding of CRC surveillance could be problematic for clinicians as well. Fear of recurrence is one of the most important concerns among survivors of cancer [12]. They can experience significant anxiety about the risk for recurrence, which can be out of proportion to their actual risk and look to their clinicians to alleviate this anxiety, often with the expectation of evaluating their cancer status with a test. Clinicians may have a difficult time explaining to patients the indications and limitations of testing, the appropriate frequency, or why their visits are becoming less frequent and will eventually end after five years, especially for patients who have a high fear of recurrence and are hesitant to separate from their oncology clinicians [13]. In the event of recurrence, clinicians will have to explain that treatment for recurrence is likely to be more difficult. However, this reality could influence patients' underlying desire for testing. These very difficult and potentially time-consuming conversations require communication of difficult concepts with careful attention to use of plain language [14].

From our stakeholder surveys, there was disagreement between advocates and clinicians regarding what facts or key messages need to be discussed. Our results confirm prior reports of this disconnect and highlight the importance of patient-centered care [15, 16, 13]. Since not all patients who are identified with cancer recurrence will be eligible for curative-intent treatment, the role of intensive surveillance testing in such patients can be debated. However, compared to clinicians, fewer advocates felt that patients should know about contraindications to surveillance, or the potential for limited impact of surveillance on survival. These findings may reflect a belief that everyone has the right to receipt of care, even when treatment may not be beneficial, and that patients must continue to fight cancer by monitoring its recurrence. The data may also underpin patients' unwillingness to consider situations of medical futility in patients who might be too frail to undergo salvage surgery. Far fewer clinicians agreed that patients should know the potential harms of surveillance tests, recurrence treatment outcomes, potential treatments for recurrence, sites where recurrence could occur, and risk of recurrence. These results may suggest that clinicians are hesitant to get into specifics about recurrence, preferring to focus on the patient being "cancer free" for now. This idea is

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consistent with the results of a study analyzing patients and clinicians for post-treatment surveillance of pancreatic cancer, a disease where few options exist for treatment should recurrence be identified [13]. It could also reflect clinicians' difficulty with providing individualized information on prognosis while still providing hope [17, 18].

A limitation of this study is the small sample size; however, thematic saturation was reached within 10 to 15 interviews regarding patients' expressed knowledge and new thematic insights are unlikely to be achieved simply by interviewing more patients. The sample was also diverse with respect to education level and included patients from a safety-net hospital. Another potential limitation is the effect of the interviewer on the participants' responses. Strategies were implemented to minimize the impact of the interviewers on the participants, such as, asking open ended questions, avoiding leading questions, and not offering an opinion when queried. The generalizability of the results from the stakeholder survey is limited because the clinicians and advocates are highly engaged in research as part of their involvement in the National Cancer Institute Community Oncology Research Program. The advocates may not represent patients and caregivers at large as they are more engaged and knowledgeable about post-treatment surveillance for cancer. Since the survey was anonymous, we did not collect any additional demographic information from the clinicians nor patient advocates. The response rate could not be determined because the anonymous survey was distributed to attendees to the Gastrointestinal Committee and Patient Advocate Committee meetings which included individuals who may not have been clinicians nor patient advocates.

In summary, the findings from this exploratory study suggests patients have a significant knowledge gap regarding post-treatment surveillance and recurrence. There is a strong belief among advocates that clinicians should attempt to help their patients to be more informed about their disease and associated treatments. Patients need educational interventions to address these gaps to be more active in their care. A prior study found that survivors of cancer were unsatisfied with the available cancer information and that the need for cancer information decreased over time, but only among women [19]. This latter study included individuals who were beyond the 5-year post-treatment surveillance period; thereby, limiting this findings relevance for patients during the post-treatment surveillance period. A more recent study with patients found that the need for information declined over time [20]. Clinicians would also benefit from interventions to promote conversations about post-treatment surveillance of CRC that more closely align with the information needs of patients. One promising approach is educational interventions combined

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with communication skills training for clinicians. The communication skills training could focus on scaffolding clinicians' ability to share information that is responsive to each patients' desire and need for information, e.g., how much. This approach recognizes that patients differ in the amount of information they want. For instance, some patients want as much information as possible and others may be overwhelmed by too much information [21]. Such interventions could help patients and clinicians be clear about the goals of care during post-treatment surveillance and recurrence, resulting in more patient-centered care.

CONTRIBUTORS

LML contributed to the conceptualization and design, collection and assembly of data, data analysis and interpretation, manuscript writing, and final approval of manuscript. RJV contributed to the conceptualization and design, data interpretation, manuscript writing, and final approval of manuscript. AC contributed to the collection of data, data analysis and interpretation, manuscript writing, and final approval. APH contributed to data collection and interpretation, manuscript editing, and final approval of manuscript. YNY, KVL, SM, JAM, and PG contributed to data interpretation, manuscript writing, and final approval of manuscript. GJC contributed to the conceptualization and design, data analysis and interpretation, manuscript writing, and final approval of manuscript.

DATA SHARING STATEMENT

The deidentified transcripts and survey data can be obtained by request from the PI, George Chang. GChang@mdanderson.org

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CONFLICTS OF INTEREST

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Fig. 1 Comparing stakeholder responses

This figure presents the stakeholder responses to what they feel patients should know about surveillance following curative resection of their colon or rectum. The values presented are in percentages. Abbreviations: GI, gastrointestinal.

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Table 1. Patient Knowledge Coding Framework

Code	Definition
Stage of diagnosis	• No: Does not accurately state the stage of diagnosis. • Yes: Able to accurately state the stage of diagnosis.
Site of diagnosis	• No: Does not accurately state the site of diagnosis. • Yes: Able to accurately state the site of diagnosis.
How the cancer was detected	• No: Unable to express how his or her cancer was detected. • Yes: Able to express how his or her cancer was detected.
Treatment modality and sequence	• Low: Does not accurately describe or provide any details about how the cancer was detected. • Medium: Provides more detail regarding treatments such as sequence and type of surgery or doses of chemotherapy. • High: Provides correct facts about modality and sequence, uses the correct terms for treatment regimen (e.g., can name the chemotherapy).
Surveillance tests (e.g., CEA, endoscopy, colonoscopy, imaging)	• Low: Does not name the tests or names one test. • Medium: Can list some tests (2/4). • High: Knows most of the tests (3/4) or why they were being done.
Harms of surveillance testing	• Low: Is not able to list any harms of testing. • Medium: Knows that risks exist but cannot explain or has poor understanding of the implications. • High: Has realistic understanding/quantification of harms. (ex. Radiation exposure secondary cancer risk, but it is very low; false positives as a risk of over-surveillance)
Frequency of surveillance tests	• Low: Has no idea. • Medium: Has some idea of testing frequency but is not communicated clearly/correctly. • High: Differentiates the different timing between the tests.
Duration of follow-up	• Low: Has no idea. • Medium: Has some concept of duration. • High: Understands and can communicate duration; makes reference to appropriate timeline (ex. 5 years).
Purpose of surveillance	• Low: Unable to express the rationale for testing. • Medium: Able to express to make sure cancer is not coming back. • High: States that surveillance is to monitor for recurrence and toxicity for long-term effects, references quality of life, or life planning.
Site of recurrence	• Low: Believes that recurrence will be more likely to come back in the colon or has no idea where recurrence will occur. • Medium: Believes that recurrence will occur somewhere other than the colon. • High: Differentiates between distant and local recurrence, and/or able to describe that recurrence will likely occur in the liver or lungs.
Sense of risk for recurrence	• Low: Cannot describe or unsure of his or her risk for recurrence. • Medium: Has a general sense of risk but lacks detail. • High: Appropriately characterizes his or her risk (e.g., risk of recurrence can be different for people; distant is higher risk than local; earlier in post-treatment surveillance the risk is higher).

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Table 1. Patient Knowledge Coding Framework

Code	Definition
Natural history of recurrence	• Low: Does not understand how recurrence develops. • Medium: Has a broad understanding of recurrence development. • High: Shows understanding of recurrence development.
Treatment options for recurrence	• Low: Is unable to describe or believes treatment for recurrence will be easy and straightforward or like what they had initially. • Medium: Mentions some options for treatment of recurrence and/or states that treatment will be different from the treatment for their primary CRC. • High: Understands that treatment will be difficult.
Likelihood of cure	• Low: Believes the likelihood of cure is high or has no idea. • Medium: Knows that it may be harder to cure but lacks complete understanding. • High: Knows that recurrence is very difficult to cure.

Abbreviations: CEA, carcinoembrionic antigen; CRC, colorectal cancer.

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Table 2. Patient Characteristics (n=31)

	n (%)
Age (median, IQR)	60 (53-68)
Gender	
Male	19 (61.3)
Female	12 (38.7)
Race	
White	22 (71.0)
Black	5 (16.1)
Other	4 (12.9)
Ethnicity	
Non-Hispanic	28 (90.3)
Hispanic	3 (9.7)
Education	
High school or less	10 (32.3)
Some college/vocational training	6 (19.4)
College	10 (32.3)
Advanced degree	5 (16.1)
Marital status	
Married	22 (71.0)
Not married	9 (29.0)
Time from surgery (months)	
6-12	5 (16.1)
13-36	20 (64.5)
37-48	6 (19.4)
Tumor site	
Colon	21 (67.7)
Rectum	10 (32.3)
Stage at diagnosis	
Stage I	3 (9.7)
Stage II	5 (16.1)
Stage III	23 (74.2)

Abbreviations: IQR, interquartile range.

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Table 3. Patient Knowledge of Post-treatment Colorectal Cancer Surveillance and Recurrence

	Mentioned n (%)	Quality of expressed knowledge[a]		
		Low n (%)	Medium n (%)	High n (%)
Treatment modality and sequence	31 (100.0)	1 (3.2)	23 (74.2)	7 (22.6)
Types of surveillance tests	30 (96.8)	5 (16.7)	14 (46.7)	11 (36.7)
Frequency of surveillance tests	31(100.0)	8 (25.9)	21 (67.7)	2 (6.5)
Harms of surveillance testing	21 (67.7)	9 (29.0)	11 (52.4)	1 (4.8)
Duration of surveillance	24 (77.4)	10 (41.7)	7 (29.2)	7 (29.2)
Purpose of surveillance	31 (100.0)	5 (16.1)	20 (64.5)	6 (19.4)
Site of recurrence	27 (87.1)	20 (74.1)	4 (14.8)	3 (11.1)
Sense of risk for recurrence	24 (77.4)	16 (66.7)	5 (20.1)	3 (12.5)
Natural history of recurrence	19 (61.3)	14 (73.1)	4 (21.1)	1 (5.3)
Treatment options for recurrence	26 (83.9)	21 (80.1)	5 (19.2)	0 (0.0)
Likelihood of cure	24 (77.4)	15 (62.5)	8 (33.3)	1 (4.2)

[a]The quality of expressed knowledge is based upon the denominator of those mentioning the knowledge element.

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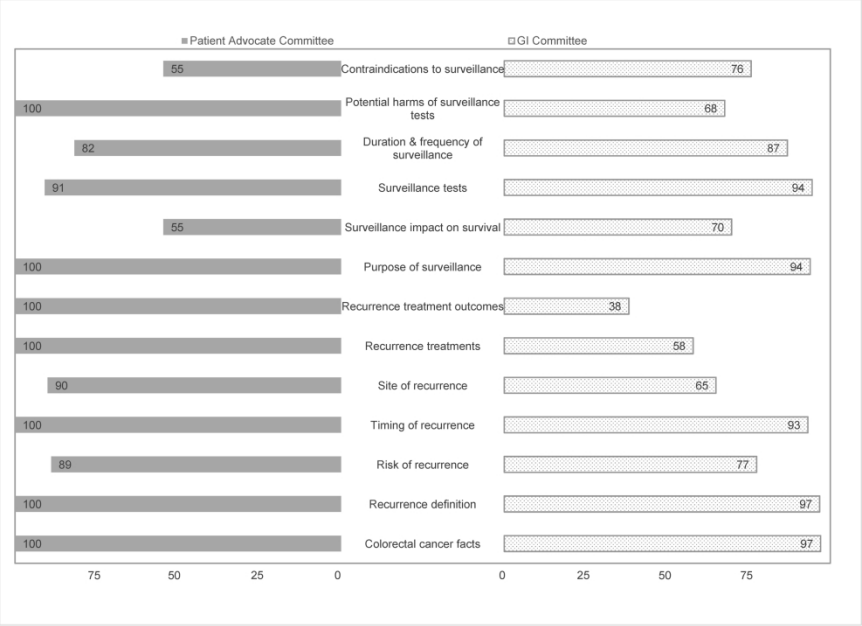

Fig. 1 Comparing stakeholder responses
This figure presents the stakeholder responses to what they feel patients should know about surveillance following curative resection of their colon or rectum. The values presented are in percentages.
Abbreviations: GI, gastrointestinal.

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Audience Response Questions

- We are creating a support tool for shared decision making regarding post-treatment surveillance.
- What do you want your patients to know about recurrence and follow up?

Possible Answers:

1. **Agree**: patients should be informed about the presented item
2. **Neutral**
3. **Disagree**: informing patients about the presented item is not important

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1. Colorectal cancer facts?

- General information about colorectal cancer, its diagnosis, risk factors, types of treatment and associated side effects
- Differences between colon and rectal cancer
- Definition of familial cancers

	Agree	Neutral	Disagree
Response	A	B	C

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2. What does it mean to have recurrence?

- Definition of recurrence
- Local vs distant
- Recurrence vs. new primary
- Natural history, death from disease

	Agree	Neutral	Disagree
Response	A	B	C

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3. How *often* do patients get recurrence?

- Association between primary tumor site and stage at diagnosis
- Impact of prior treatments on recurrence risk

	Agree	Neutral	Disagree
Response	A	B	C

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4. *When* is recurrence most likely to occur?

- Most recurrences occur within 2-3 years of completing treatment
- Risk decreases with time

	Agree	Neutral	Disagree
Response	A	B	C

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5. *Where* is recurrence most likely to occur?

- Most common sites of recurrence and how they are identified
- Relationship to primary tumor sites

	Agree	Neutral	Disagree
Response	A	B	C

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6. What are the possible *treatments* for recurrence?

- Impact of the site of recurrence on treatment options
- Role of surgical or radiotherapeutic treatments
- Chemotherapy treatments

	Agree	Neutral	Disagree
Response	A	B	C

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7. What are the *outcomes* after treatment for recurrence?

- Proportion of patients who could undergo curative intent salvage surgery
- Goals of palliative chemotherapy
- Impact of treatments on overall survival

	Agree	Neutral	Disagree
Response	A	B	C

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8. What are the *goals* of post-treatment follow-up?

- Detection of treatable recurrence
- Monitoring of long-term treatment effects
- Reassurance
- Quality of life and future-planning
- Continuity of care

	Agree	Neutral	Disagree
Response	A	B	C

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9. What is the impact of follow-up on survival?

- Data from randomized trials of follow-up intensity

	Agree	Neutral	Disagree
Response	A	B	C

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10. What are the types of *tests* used for surveillance?

- Detailed information regarding
  - Imaging (e.g. CT, MRI, PET)
  - CEA (how it is used, when it is helpful)
  - Endoscopy (what it is designed to identify)
  - Clinical evaluation

	Agree	Neutral	Disagree
Response	A	B	C

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11. How *long* and how *frequently* should testing be performed?

- Impact of stage and time since treatment completion

	Agree	Neutral	Disagree
Response	A	B	C

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12. What are the potential *harms* of testing?

- False positive findings and unnecessary procedures
- Anxiety
- Radiation exposure
- Complications of endoscopy

	Agree	Neutral	Disagree
Response	A	B	C

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13. Are there any situations in which surveillance may not be beneficial?

- Advanced age
- Advanced comorbidities
- Patient desire to not be followed
- Patient preference for no further treatment

	Agree	Neutral	Disagree
Response	A	B	C

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Discussion

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Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No	Item	Guide questions/description	Page
Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	6
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*	6
3.	Occupation	What was their occupation at the time of the study?	6
4.	Gender	Was the researcher male or female?	6
5.	Experience and training	What experience or training did the researcher have?	6
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	6
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e.*g. personal goals, reasons for doing the research*	6
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. *Bias, assumptions, reasons and interests in the research topic*	6
Domain 2: study design			
Theoretical framework			
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*	6

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No	Item	Guide questions/description	Page
Participant selection			
10.	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*	6
11.	Method of approach	How were participants approached? e.*g. face-to-face, telephone, mail, email*	6
12.	Sample size	How many participants were in the study?	7
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	Not reported
Setting			
14.	Setting of data collection	Where was the data collected? e.*g. home, clinic, workplace*	6
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	Not reported
16.	Description of sample	What are the important characteristics of the sample? *e.g. demographic data, date*	7
Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	6
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	NA
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	6
20.	Field notes	Were field notes made during and/or after the interview or focus group?	NA
21.	Duration	What was the duration of the interviews or focus group?	6

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No	Item	Guide questions/description	Page
22.	Data saturation	Was data saturation discussed?	11
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	6
Domain 3: analysis and findings			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	6
25.	Description of the coding tree	Did authors provide a description of the coding tree?	17
26.	Derivation of themes	Were themes identified in advance or derived from the data?	7
27.	Software	What software, if applicable, was used to manage the data?	7
28.	Participant checking	Did participants provide feedback on the findings?	6
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.*g. participant number*	8-9
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Yes
31.	Clarity of major themes	Were major themes clearly presented in the findings?	8-9
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	8-9

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