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ORIGINAL ARTICLE

Determinants of Rectal Cancer Patients' Decisions on Where to Receive Surgery: a Qualitative Analysis

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Abstract

Background Current literature suggests surgeons who perform large volumes of rectal cancer resections achieve superior outcomes, but only about half of rectal cancer resections are performed by high-volume surgeons in comprehensive hospitals. Little is known about the considerations of patients with rectal cancer when deciding where to receive surgery.

Methods A purposive sample of stage II/III rectal adenocarcinoma survivors diagnosed 2013–2015 were identified through the Iowa Cancer Registry and interviewed by telephone about factors influencing decisions on where to receive rectal cancer surgery.

Results Fifteen survivors with an average age of 63 were interviewed: 60% were male, 53% resided in non-metropolitan areas, and 60% received surgery at low-volume facilities. Most patients considered surgeon volume and experience to be important determinants of outcomes, but few assessed it. Recommendation from a trusted source, usually a physician, appeared to be a main determinant of where patients received surgery. Patients who chose low-volume centers noted comfort and familiarity as important decision factors.

Conclusion Most rectal cancer patients in our sample relied on physician referrals to decide where to receive surgery. Interventions facilitating more informed decision-making by patients and referring providers may be warranted.

Keywords Rectal cancer · Patient decision making · Qualitative analysis

Introduction

Several studies have demonstrated that patients with rectal cancer treated by high-volume, specialized surgeons or hospitals receive more guideline-recommended care,[1–4] have improved sphincter preservation rates,[5–13] lower 30-day postoperative procedural interventions,[14] lower postoperative mortality,[12,15–18] decreased local recurrence rates,[7,10,13] and greater overall survival[5,6,10,19–21] compared to patients treated by lower volume centers. Despite evidence of a volume-outcome relationship, less than half of rectal cancer resections are performed by high-volume surgeons in comprehensive facilities.[22] Few studies have shown evidence of a major shift toward high-volume centers for rectal cancer treatment, though shifts have been found for other gastrointestinal cancers.[23,24] In addition, previous studies have not focused on determining factors driving patient decisions on where to receive care for rectal cancer, or how much influence physician referrals have on their decision-making.

Patients may be largely unaware how health system characteristics can influence referral patterns for rectal cancer. For example, health care systems generally encourage referrals to in-system providers, such that there may be pressure on a diagnosing provider to refer new rectal cancer patients to surgeons within the same system, even if the available surgeons

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do not perform high volumes of rectal cancer resections. Those not employed by hospital systems may still have affiliations or longstanding relationships with certain surgeons that restrict their referral patterns. Furthermore, patients may not realize that primary care physicians and gastroenterologists, by virtue of training and professional specialty, are not typically involved with staging, treatment, or follow-up of rectal cancer. They have little expertise in the multidisciplinary treatment of rectal cancer, are often unaware of the specifics of rectal cancer surgery, and may not know there is a difference in care and outcomes at a high-volume versus low-volume centers. It has been shown among breast cancer patients that those who reported provider or health plan-based referral were less likely to be treated in a National Cancer Institute (NCI) designated cancer center.[25] Patients may therefore be erroneously assuming they will be referred to the most qualified surgeon or cancer center.

This study aimed to assess patient perceptions and factors influencing decisions on where to seek rectal cancer treatment. Identification of decision-making factors is critical to the development of strategies to improve patient decision-making and patient-provider communication to optimize access to high-quality care and outcomes.

Materials and Methods

This study was guided by the Theory of Reasoned Action (TRA)[26] and the Theory of Planned Behavior (TBP),[27] which are illustrated in Fig. 1. TRA focuses on relationships between beliefs (behavioral and normative), attitudes, intentions, and behavior. Fishbein's work illustrated that attitude toward an object (e.g., receiving rectal cancer surgery from an experienced surgeon/hospital) is a poor predictor of behavior, whereas attitude toward a behavior with respect to that object (e.g., performing research and selecting surgeons or hospitals based on experience/volume) is a good predictor of behavior. TBP is an extension of TRA that attempts to account for factors outside of the individual's control that may affect his/her intention and behavior. Thus, a person will make more of an effort to perform a behavior when his/her perception of behavioral control is high.[27] Rectal cancer patients' decision-making process on where to receive treatment is expected to be based on attitudes, subjective norms (e.g., how the people they respect will view their decision), and perceived behavioral control.

Patient Selection

Patients eligible for participation were diagnosed with stages II/III rectal adenocarcinoma between 2013 and 2015 (inclusive) and underwent rectal resection. Subjects were identified from the Iowa Cancer Registry, which has been a part of the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program since 1973. A stratified purposeful sampling approach was used whereby we recruited individuals from each of the following strata: age < 65 vs. ≥ 65, male vs. female, metropolitan, and non-metropolitan as defined by the 2013 Rural-Urban Continuum Codes designated by the US Department of Agriculture,[28] and receipt of surgery in a low-volume vs. high-volume facility. High-volume facilities were defined as those with over 400 beds that were accredited by the Commission on Cancer as a Comprehensive Community or Academic Cancer Center and performed more than 35 rectal cancer resections annually. All other facilities were considered low-volume. All eligible participants were mailed information about the study and notified they would be called 1 week later by Registry staff. During the introductory call, patients were asked if they would agree to be interviewed for the study by telephone. Those who agreed were either interviewed immediately or worked with Iowa Cancer Registry staff to schedule an interview.

Data Collected

Semi-structured interviews were conducted with rectal cancer patients about their decision-making processes. To develop the interview content, a draft interview guide was developed following the theoretical framework and including key factors from the literature. Three cognitive interviews (i.e., think-a-loud methods) were conducted to assess clarity of the questions, improve the wording of the interview guide, and evaluate if questions were interpreted as intended,[29] and modifications were made as necessary. Interviews included 12 open-ended questions and four closed-ended questions with follow-up probes that covered treatment decision-making processes and factors, as well as attitudes toward the importance of surgeon experience and volume. The interview guide is provided in Fig. 2. All interviews were conducted by two team members trained in qualitative methods. On average, interviews lasted 45 min. All subjects provided verbal consent to participate in the study and to have audio-recorded interviews. Interviews were transcribed verbatim. Patients were provided $25 as compensation for participation. This study was approved by the University of Iowa Institutional Review Board.

Data Analysis

A thematic analysis approach was utilized to provide insight into patients' thought processes and meanings surrounding

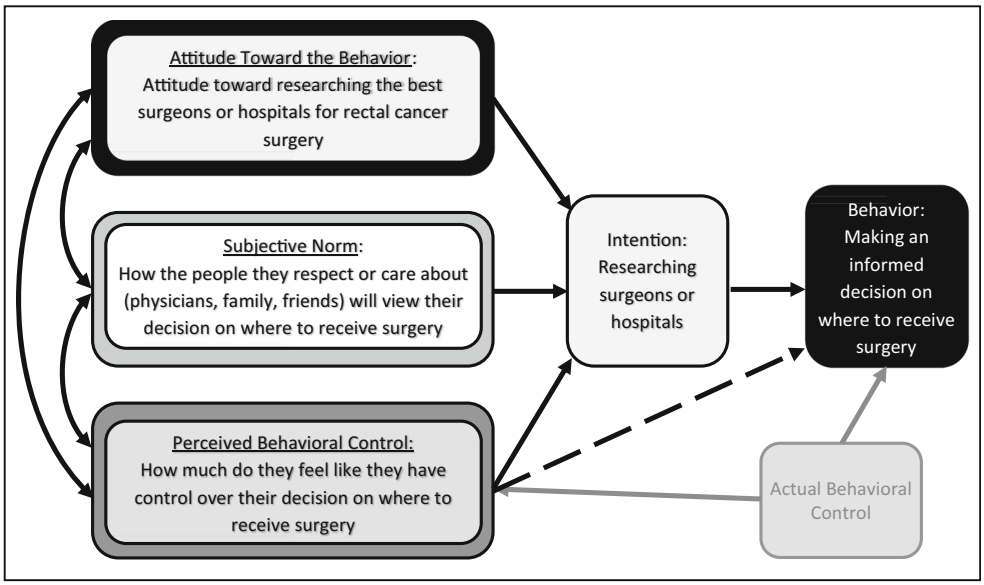

Fig. 1 Theoretical framework based on the Theory of Reasoned Action and the Theory of Planned Behavior

treatment decisions.[30] The study PI and both interviewers reviewed the first five patient interview transcripts and generated initial codes inductively using multiple coding to compare and distinguish sections of text into specific categories.[31] Multiple coding involves each team member bringing observations and descriptions about the data to team meetings to discuss experiences about the analytic process and describe their codes in detail. Discussions involved the similarities, differences, and patterns within and between codes. This process is similar to constant comparison,[32] except team members were not conducting analyses in isolation and were actively comparing and contrasting analyses. Overall, discussions revealed high levels of agreement across team members. In instances of differing opinions on how themes and ideas should be grouped together, members were able to reach a consensus through collective reflection and meshing of interpretations until a list and description of codes were developed that were agreed to be reflective of the data.

Through this process, codes were adapted, redefined, incorporated, and dropped until team members agreed they reached a list of codes that most reflected shared interpretations of participant experiences. Saturation was reached by which sampling until redundancy was evident and no new themes emerged from the data.[33] The dataset was first analyzed as a whole to capture themes across all patients. Then, the dataset was split into two groups as a function of where patients received treatment (low-volume vs. high-volume centers) and analysis was undertaken to identify where themes were comparable or contrasting across groups.

Demographic and closed-ended responses were described and summarized via univariate analysis. Mean and standard deviation were calculated for age as a continuous variable and percentages for categorical variables. Characteristics between participants and non-participants were compared using *t* tests for age and Chi-square tests for the remaining categorical variables. Analyses were conducted using SAS version 9.4 (SAS Institute, Cary, NC).

Results

Demographics

Figure 3 illustrates the numbers of subjects recruited and interviewed. Consistent with recommendations in the literature for qualitative research sample size, we aimed to complete and analyze a minimum of 12–15 interviews before determining if saturation had been reached, as previous qualitative methods researchers have suggested that saturation often occurs after 6 to 12 interviews, particularly for studies with narrow topics and high-data quality.[34] Recruitment letters were therefore mailed to 35 people based on an estimated participation rate of 40–50%. A total of 15 people were interviewed, and their demographic characteristics are displayed in Table 1. While analyzing the final three interview transcripts, study team members agreed no new themes had emerged beyond those identified from the initial 12 interviews indicating that saturation had been reached; no additional recruitment letters were mailed.

The average age of participants was 63.3 years of age; 8 were under age 65 and 7 were over age 65. More males ($n = 9$) participated than females ($n = 6$). The majority of the participants were married (60%), insured (87%), and resided in counties that were categorized as non-metropolitan areas (53%) and had less than 10% of its population living below poverty level (67%). In addition, the majority of participants received surgery for their rectal cancer at low-volume facilities

Open Ended Questions:

1. Thinking back to when you first found out you had rectal cancer, could you describe how you decided where to go for cancer care?
2. I'm also interested in understanding the path you took. Do you happen to remember what type of doctor you talked to first? What kinds of doctors did you see thereafter?
3. Who did you turn to for help when you were deciding where to have surgery? Who all did you talk to for advice? *[Probes: Whose input did you value the most? How much did you feel like you had to go where that person told to you to go? What did that person think of your decision on where to receive treatment?]*
4. Besides the people you mentioned, what other sources of information did you use to learn about rectal cancer treatment? *[Probes: Did you use the internet? Talk to friends or family?]*
5. How important was it for you to be involved in the decision on where to receive surgery for your cancer?
6. How much did you feel like you had a choice of which surgeon or hospital to go to for surgery?
7. Did anything make it hard for you to choose a surgeon or hospital?
8. Can you describe some characteristics of a surgeon that might make the typical patient with rectal cancer choose him or her? *[Probes: Which do you think is the most important?]*
9. Many people with rectal cancer have their surgery performed by a general surgeon, which is a type of surgeon who performs many different types of operations. And some people have their surgery performed by a special type of surgeon who only performs certain types of operations – either a colorectal surgeon or a surgical oncologist. Do you happen to remember the type of surgeon who removed your rectal cancer?
10. How did your surgeon's experience level play a role in your choice of where to get surgery for cancer?
11. Can you describe some characteristics of a hospital that might make the typical patient with rectal cancer choose to get care there?
12. What outcomes of surgery were the most important to you?

Closed Ended Questions:

13. Surgeons have different levels of experience in performing surgery to remove rectal cancer. How would you describe your surgeon's experience level? Response Options: Extremely experienced/ Very experienced/ Moderately experienced/ Slightly experienced/ Not at all experienced *[Probes: How do you think the typical patient with rectal cancer can tell that their surgeon had enough experience to remove their rectal cancer? Do you think the typical patient with rectal cancer asks their surgeon any questions about his/her experience with treating rectal cancer? If so, what questions do they think ask the surgeon about his/her experience?]*
14. How satisfied are you with the surgeon you chose? [Response Options: Extremely satisfied/ Very Satisfied/ Moderately Satisfied/ Slightly satisfied/ Not at all satisfied] *[Probes: If you had to do everything over again, would you choose the same surgeon? Would you recommend this surgeon to a friend or family member? What kinds of things made you satisfied/unsatisfied with the surgeon?]*
15. How satisfied are you with the hospital you chose? Response Options: Extremely satisfied/ Very Satisfied/ Moderately Satisfied/ Slightly satisfied/ Not at all satisfied *[Probes: If you had to do everything over again, would you choose the same hospital? Would you recommend this hospital to a friend or family member? What kinds of things made you satisfied/unsatisfied with the hospital?]*
16. We understand that on average, general surgeons do a few rectal cancer surgeries per year, whereas specialized colorectal surgeons and surgical oncologists do a large number of rectal cancer surgeries per year (e.g., about one per week). How much do you believe the number of times a surgeon performs rectal cancer surgery makes a difference in terms of outcomes? Response Options: Very much believe/ Somewhat believe/ Neutral/ Somewhat do not believe/ Do not believe *[Probes: Could you explain why you believe the number of times surgeons perform rectal cancer surgeries [makes/does not make] a difference?]*

Fig. 2 Interview guide

(60%). When comparing characteristics of study participants to non-participants, only receipt of surgery at low-volume facilities differed significantly, with the minority of non-participants (25%) receiving surgery in low-volume facilities (Table 1).

The average age of patients going to high-volume centers was 55 years vs. 64 years for those going to low-volume centers. Half of patients going to high-volume centers were female vs. one-third of those going to low-volume

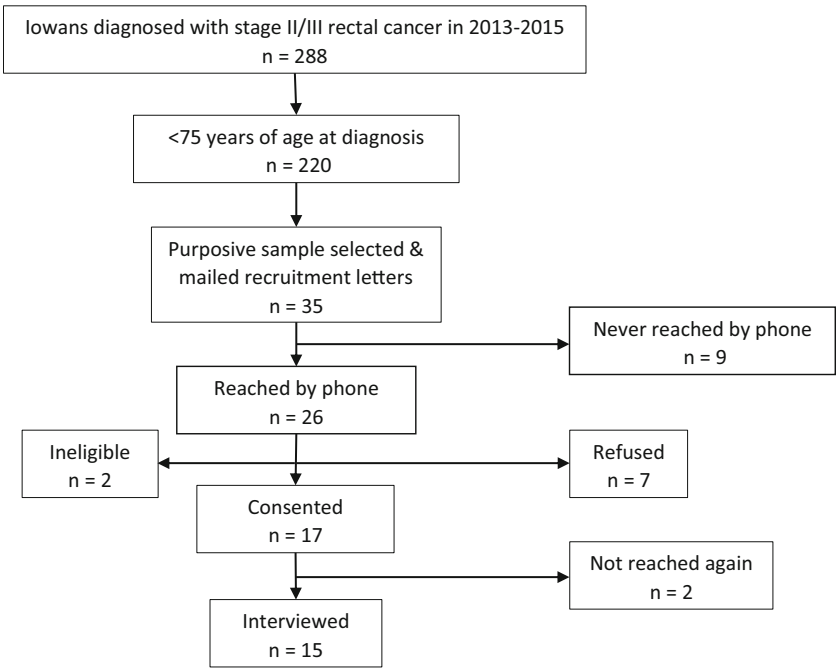

Fig. 3 Diagram of study participation

centers. Roughly half of patients who went to either high- or low-volume centers resided in metropolitan areas. All but one of the patients going to high-volume centers were married compared to just over half of those going to low-volume centers. None of the differences were statistically significant.

Themes

The following paragraphs describe emergent themes during patient interviews. Specific quotations illustrating themes are displayed in Table 2 and are stratified by volume of the facility where the patient underwent surgery (i.e., low-volume vs. high-volume). Most themes relate to patients' attitudes about selecting a surgeon or hospital based on experience with, or volume of, rectal cancer procedures, and beliefs about how people they care about or respect would view their decision. The final theme describes patients' perceived control over the decision on where they received surgery for rectal cancer.

Physician Referrals and Recommendations

A salient theme across both low- and high-volume groups was the value and trust that patients placed in their physician's ability to make the right treatment choice and recommendation. Physician recommendations were often the sole consideration for patients on where to go for rectal cancer surgery and which surgeon to choose. Patients trusted physician ability to choose a surgeon and followed physician recommendations willingly and compliantly.

Surgeon Explanations and Knowledge of Cancer and Procedures

A marked theme among patients who received surgery at low-volume centers was that that they valued their surgeon's ability to explain surgical procedures and knowledge of rectal cancer in a way that was understandable. Patients illustrating this theme were satisfied with the simplicity of explanations given to them, and some mentioned being particularly satisfied when their surgeon drew them diagrams or pictures to illustrate procedures and other anatomical aspects. This theme was much less marked among patients who received surgery at high-volume centers; only a few mentioned being content with the surgeon's ability to explain information in a way that made them seem more confident or competent.

Surgeon Personality and Demeanor

Another prominent theme in the low-volume group was that they valued the surgeon's ability to make them feel comfortable as well as the surgeon's personal characteristics and demeanor. Patients in this group noted aspects, such as surgeon religiosity and a positive attitude, as important to treatment decisions. Only rarely did patients in the high-volume group describe surgeon personality and demeanor as valuable.

Personal Knowledge of Surgeon

Some patients who chose low-volume centers mentioned knowing the surgeon personally or knowing of the surgeon

Table 1 Characteristics of study population compared to non-participants

Subject characteristic	Participants $n = 15$ n (%)	Non-participants $n = 20$ n (%)	p value*
Age			
Average current age (± SD)	63.3 (10.5)	63.3 (8.8)	0.90
Range current age	43–74	48–75	
Under age 65 at diagnosis	8 (50%)	13 (65%)	0.49
Over age 65 at diagnosis	7 (50%)	7 (35%)	
Year of diagnosis			
2013	4 (27%)	9 (45%)	0.47
2014	9 (60%)	8 (40%)	
2015	2 (13%)	3 (15%)	
Sex			
Male	9 (60%)	10 (50%)	0.56
Female	6 (40%)	10 (50%)	
Marital status			
Single or unknown	3 (20%)	4 (20%)	0.68
Married	10 (67%)	11 (55%)	
Divorced or widowed	2 (13%)	5 (25%)	
Stage			
II	7 (47%)	7 (35%)	0.49
III	8 (53%)	13 (65%)	
Insurance			
Private	6 (40%)	10 (50%)	0.64
Medicare or other federal (e.g., VA)	7 (47%)	9 (45%)	
Unknown or uninsured	2 (13%)	1 (5%)	
Percent of county below poverty level			
< 10% poverty	10 (67%)	9 (45%)	0.20
> 10% poverty	5 (33%)	11 (55%)	
Residence**			
Metropolitan	7 (47%)	8 (40%)	0.69
Non-metropolitan	8 (53%)	12 (60%)	
Surgical facility volume			
High-volume	6 (40%)	15 (75%)	**0.04**
Low-volume	9 (60%)	5 (25%)	

*p value based on t test for age and Chi-square test for all other variables

**Based on 2013 USDA Rural Urban Continuum Codes (https://www.ers.usda.gov/data-products/rural-urban-continuum-codes/)

and surgeon's relatives as a factor in choosing a surgeon. These patients valued personal connections to their surgeon, including having a working or business relationship with a surgeon and knowing the surgeon's relatives who had previously treated family members. None of the patients who chose high-volume centers mentioned personal connections to a surgeon.

Past Experience with Hospital

Many patients in the low-volume center group mentioned having prior familiarity with the hospital where they chose to have surgery due to receiving prior services there or working with individuals in that hospital. Patients in this group reported valuing the familiarity of the chosen hospital. No patients in the high-volume group reported choosing hospitals they had past experience with or that were familiar.

Continuing at Initial Hospital Where Colonoscopy/Cancer Diagnosis Was Received

Most patients choosing low-volume centers mentioned staying at the hospital where they had their colonoscopy or where their initial cancer diagnosis was received. Reasons mentioned for this choice included simplicity of staying in the same location and trusting providers in the care that was

Table 2 Illustrative quotations by theme and by receipt of surgery at low-volume vs. high-volume centers

Themes	Low-volume centers	High-volume centers
Physician referrals and recommendations	"I figured the doctors knew what they're doing and they'd know best, so I just went with the flow" (male < 65 metro)	"So that's kind of what the doctor recommended, so that's kind of, you know, we followed his recommendations." (Male < 65 Metro)
	"Because he was recommended. My general surgeon felt very comfortable with that group of physicians." (Male > 65 Non-Metro)	"He was the gentleman that was recommended to us." (Female < 65 Non-Metro)
	"I just, like I say, I listen to them and do what they said. So, yeah, I did not really do any study on my own…I suppose I could've -- I could have looked into their credentials, but I trusted them, so I went for it." (Male > 65 Metro)	"So I kind of let my primary doctor lead me in the right direction…I did take his advice because I trusted him. And I didn't know what to do at the time or where to go or questions to ask, anything. I was still just kind of blowed out of the water." (Female < 65 Metro)
Surgeon explanations and knowledge of cancer and procedures	"They explained things to me just the way I wanted to hear it. And that's what made me choose to go there." (Male < 65 Non-Metro)	"I did a little research on him and -- not much. But in my talking with him, he seemed quite competent, and I was hopeful with what he was telling me, and I went with him." (Female < 65 Non-Metro)
	"She was very explicit as what was going to happen and what was going to happen afterwards." (Male > 65 Non-Metro)	"And I thought he was so much more confident with what he was telling me. I could understand everything that he was saying, which is a big plus with something like this…I felt very comfortable with him and what he was telling me. I mean he drew me pictures, he explained things in words that we understood, and he gave it a very positive outlook." (Female < 65 Metro)
	"As far as explain it right down to a point now that he'll show you exactly what he's going to do and where he does it." (Male > 65 Non-Metro)	
Surgeon personality and demeanor	"She's very bedside-mannered, easy to talk to, answers any question that you have, and just makes you feel very comfortable about the surgery." (Male > 65 Non-Metro)	"Very good personality, just he was very at ease, very knowledgeable, and very good reputation, but his demeanor was very good" (Male < 65 Metro)
	"I think it's just because he's -- he puts you in really a nice spot. He is very -- well, for one thing, he's very religious, and he's very concerned about you." (Female > 65 Non-Metro)	
	"You know, this is not nothing, we'll take care of it. That's how he was." (Male < 65 Metro)	
Personal knowledge of surgeon	"You know, I had a history with him before. Not for the cancer, but for other things I'm having issues with…I don't like new things, especially when you're comfortable with the people you already know." (Male < 65 Metro)	
	"You know, I knew Dr. _____ really, probably quite well because I also knew his wife because I moved his wife, and I moved him…I guess it comes right back to where I knew the man pretty well." (Male > 65 Non-Metro)	
	"I went to see my assistant physician there, in _____. And she in turn -- well, yeah. She in turn then gave me four surgeons. And out of the four, I knew, not directly, but I knew one. He treated my -- his dad was my mother's doctor in ____. And I knew he would be a good surgeon because his father was a very good surgeon. They are very good people." (Female > 65 Non-Metro)	
Past experience with hospital	"I've been going to _____ and ____ for years and they've always did me right. I don't want to go somewhere I'm not familiar with." (Male < 65 Metro)	
	"…my wife and I both worked at the hospital for five or six years, so we are very familiar with the doctors there. And we decided just to stay here." (Male > 65 Non-Metro)	
	"This is kind of a bigger hospital, I used to work with a lot of people in the hospital, so I knew a lot of people in it."(Male > 65 Non-Metro)	
	"I don't know. I just, you know, stayed there at _____, because that's where I was at. And at that point, you're	

Table 2 (continued)

Themes	Low-volume centers	High-volume centers
Continuing at initial hospital where colonoscopy/cancer diagnosis was received	just kind of in limbo, so you're asking, 'Well, who's the best?' and you're just hoping that they're telling you the truth." (Female < 65 Non-Metro)	
	"I went with the same doctor -- surgeon." "After I talked with my doctor and talked with the person that did the colonoscopy, I decided that I would have it done right there with the same people that talked with me about it." (Male < 65 Non-Metro)	
	"I was already at the _____, so, yeah, I just went there and did what they told me to." (Male > 65 Metro)	
Recommendations of family and friends	"I have a cousin that is going through cancer, and the doctor he had is who I wanted because he does all the research and everything on the doctors. So he was recommended..." (Female < 65 Non-Metro)	"My sister talked me out of having the general surgeon here do it. She said I needed a specialist and it didn't take very long for me to realize that's what I needed." (Male > 65 Non-Metro)
		"My husband's cousin had colon cancer at the same time, and he was using the same surgeon." (Female < 65 Non-Metro)
		"I have always just heard wonderful things about _____. I had a friend who was going through cancer treatment at that time too, and that is where he was going. You know, nothing else ever really entered my mind." (Female < 65 Metro)
Online research	"I didn't rely a whole lot on the internet because it kind of gets scary. So I just listened to people when they talked to me." (Female < 65 Non-Metro)	That's what my sister -- she googled him and before we had the meeting she knew that he had been a doctor for over 25 years. (Male > 65 Non-Metro)
	"No, I did not [use the internet] because I do not really use the computer. (Male > 65 Non-Metro)	"We did look some stuff up on the internet, but I kind of -- I do not really trust the information on the internet" (Male < 65 Metro)
	"No, because the doctor had told me not to go online and look it all up and get all confused and ..." (Female < 65 Metro)	"So from what I could tell, I did a little online research of him, and he had good reviews. And my local practitioners had good references of him." (Female < 65 Non-Metro)
Role of distance	"I just decided I wanted to stay in town. I have children here, and I didn't want to be out of town. And if anything would happen, I didn't want them to have to travel." (Female < 65 Metro)	"The biggest thing on the surgeons was the distance. Driving to _____ was farther away, so we chose _____. So logistics was probably about the only real consideration on the surgeons…they were close, I mean, so there was going to be a lot of trips involved so we -- you know, you try to make life as simple as you can." (Male < 65 Metro)
	"I just -- as far as, like I say, the hospital it was more or less a few blocks away, I figured that was better than traveling a distance... maybe I'm wrong, but unless it -- maybe it's something that they cannot handle, at least they'll come out and tell you." (Male > 65 Non-Metro)	"I believe it was the radiation doctor here at _____, I asked him to hook me up with one of their associates that he worked with in _____, and so I went to that one. Just because it was easier for the correspondence between the oncologist and the radiation doctor and the surgeon because they all work together here at _____." (Male > 65 Non-Metro)
	"Then, Dr. _____, he was very good explaining it to me too, that the same type of surgery I would have that Dr. _____ was going to do on me would be the same type of procedure that they would do in _____, so why drive clear up to _____ when I could have it done close." (Female > 65 Non-Metro)	
Beliefs about importance of surgeon experience and volume	"I think it's important because the more they've done, the better they are at it." (Female < 65 Non-Metro)	"Practice makes perfect." (Male > 65 Non-Metro)
	"Well, because they know what to look for and they do not -- they take everything step by step. If they see something wrong, they know more about it, they are more experienced at it." (Male < 65 Non-Metro)	"Well, I'm very familiar with what rectal surgery involves and the complications that go with it. It's a very delicate surgery, and even my local surgeon that first diagnosed it told me that he does do those surgeries, but he -- this one was delicate enough that he did not want to do it himself. Somebody that specializes and does a lot of it,

Table 2 (continued)

Themes	Low-volume centers	High-volume centers
		they know the intricacies and the fine points better than just a general surgeon." (Male < 65 Metro)
	"I think probably it's just about like anything else, the more you do them, maybe the smarter you get along the way. It's just experience, I think." (Male > 65 Non-Metro)	"I think the more experience they have and the more they have done it, the more they learn too. They are human too and they are apt to make mistakes. But I think the more experience they have, yeah." (Female < 65 Metro)
Personal assessment of surgeon experience	"Can they answer your question--if they can answer back right away without having to pause and think about it. They experienced, you know." (Male < 65 Metro)	"... if they're also involved in teaching it, they must know their stuff, you know. Or they should." (Male > 65 Non-Metro)
	"By the way that she explains things. By the way that they can give you other options on what to do. From start to finish, they followed through all the way from, like if you are reading a book, the first paragraph of the book and the last paragraph, she went through everything and she made sure that you understood explicitly." (Male < 65 Non-Metro)	"…the way he explained things, you know, I know he's been doing it for a number of years at this point in time." (Female < 65 Metro)
	"Well, he explains stuff to you. My surgeon did. We went in and, I do not know, he had kind of made some type of circle and stuff on a board. And it kind of just showed things and things that might happen and stuff." (Female > 65 Non-Metro)	
Assessment of surgeon performance by surgical outcome	"That's how we ended up staying with him all the way, and I guess it's the right decision because I come out all right." (Male > 65 Non-Metro)	"Because they got the cancer and I have fairly normal bowel function again, which in rectal cancer is not always the case. So because I am functioning pretty much normally again." (Female < 65 Non-Metro)
	"Oh, like I say, the only thing I really have to go by is the results, and I would say so far it's been, like, three years and -- so I would have to say they are very experienced. And, like I say, there's no way for me to know except for by the results." (Male > 65 Metro)	"And when everything was all said and done, my sister said I was very fortunate because a surgeon with less patience, I would have had a permanent colostomy. He just did not give up. I mean, he had troubles doing it, and he did me right." (Male > 65 Non-Metro)
	"I do not know. I guess I'm satisfied with everything. Apparently, you know, I came out of it okay." (Female > 65 Non-Metro)	"The way he handles the surgery, there was initially two surgeries scheduled for the deal, and they both went, you know pretty well. So I would say I'm very happy with the way things went initially." (Male < 65 Metro)
Perceived control regarding where to receive surgery	"Well, I suppose it was just up to me whether -- you know." "She gave me the list"(Female > 65 Non-Metro)	"I felt like I had control." (Female < 65 Non-Metro)
	"You have always got a choice. It wasn't forced upon me or anything like that. You know, I could have turned it down and gone elsewhere, or taken a second decision [sic], but looked like the first decision was the best decision to make." (Male < 65 Non-Metro)	"Oh, all of the choices were 100% mine. They laid out different options and they gave recommendations, but there was no pressure in any way, shape, or form to follow their recommendations." (Male < 65 Metro)
	"Everyone decided for me.... I went to a specialist and he told me what I had and he took care of it from there." (Male < 65 Metro)	"I was the one that made the decision." (Male > 65 Non-Metro)

already being received. None of the patients in the high-volume group reported continuing at the hospital in which a colonoscopy was performed or a diagnosis received.

Recommendations of Family and Friends

The impact of surgeon recommendations from family and friends on where to receive treatment was a far more salient theme among patients in the high-volume group. Some of the patients in this group mentioned relatives or friends who had cancer and decided to use the same surgeon they did. Only rarely did patients in the low-volume group mention that talking with family and friends and seeking treatment decision recommendations was important to them. One patient in this group mentioned a surgeon recommendation from a relative who was going through cancer treatment.

Online Research

Some of the patients choosing high-volume centers reported that they did use the Internet to get information about how long the surgeon had been practicing and to examine patient

reviews written about the surgeon. Others in this group reported not trusting online sources due to possible misinformation, or the possibility that accessing online information would make them question the choices they made. None of the patients choosing low-volume centers reported using the Internet to help them make decisions on where to receive treatment, but some did indicate that they used the Internet to pull up general information about their cancer. Others in this group mentioned that information on the Internet can be scary or confusing, or that they are not good at using the computer.

Role of Distance

Some low-volume center patients described valuing a treatment center that was closer to their home rather than traveling a distance for procedures. Patients mentioned differing aspects important to distance decisions (e.g., the surgeon explaining that the same type of procedure completed in a higher volume facility would be the same procedure done locally; personal beliefs that a surgeon would tell the patient if the surgery was too complicated to complete at a low-volume center; being dependent on adult children for travel to treatment). None of the high-volume patients mentioned distance as a factor in their decision to go to a high- vs. low-volume center. One patient did mention that distance played a role in deciding which high-volume center to go to because one was an hour and half away and the other was almost twice as far. Another patient mentioned having to choose between two high-volume centers for surgery, and ultimately chose the facility that his local oncologist was affiliated with to permit easier correspondence between his physicians.

Beliefs About Importance of Surgeon Experience and Volume

Patients in both groups elaborated on the value of surgeon experience and volume of surgeries completed and said they believed that the number of times a surgeon performs rectal cancer surgery makes a difference in terms of outcomes. Patient explanations of the importance of surgeon experience and volume included descriptions that the more procedures a surgeon performs, the better he/she will be.

Personal Assessment of Surgeon Experience

Patients across both groups mentioned knowing that their surgeon was experienced due to the way the surgical procedure or aspects about rectal cancer were explained. Surgeon explanations were described by some patients as valuable because explanations were simple and understandable to the patient. Other patients described additional ways of knowing that surgeons were experienced (e.g., when the surgeon was able to answer questions immediately after being asked or when the surgeon was involved in teaching the subject matter to others).

Assessment of Surgeon Performance by Surgical Outcome

Most patients in both low- and high-volume center groups described retrospectively knowing that their surgeon was experienced due to their personal surgical outcome being satisfactory and without complications. Patients placed value on being able to function at least somewhat normally again and stated this as a way of knowing surgeon experience. No patients reported asking their surgeon questions directly related to experience despite many stating that patients with rectal cancer should ask about surgeon experience. Patients did not generally report discussing sphincter preservation with their surgeon or factoring sphincter preservation into their decision-making process, but several commented on being pleased with their current bowel function.

Perceived Control Regarding Where to Receive Surgery

A prominent theme among patients in both low- and high-volume groups was feeling like they had a choice of where to go for surgery. In addition, most said that it was important for them to be involved in the decision about where to have their surgery and that they had satisfactory involvement in the decision. Some of the patients specifically mentioned that they were presented with options to get a second opinion elsewhere, but none reported doing so.

Discussion

Patients with rectal cancer considered experience and volume to be important determinants of outcomes, but few attempted to assess these characteristics prior to choosing a surgeon or hospital. Only those who chose high-volume centers reported searching online to gather information. Overall, advice from friends, relatives, primary care physicians, and gastroenterologists seemed to be the most critical factor in choosing a surgical center for both low- and high-volume groups. Patients who chose high-volume centers tended to have individuals close to them (e.g., a local surgeon, relative with medical knowledge) who recommended they go to larger centers for treatment. Conversely, patients who chose low-volume centers did not seem to have individuals close to them who recommended care at a high-volume center. Furthermore, low-volume center patients did not report having local surgeons who advocated for going to a higher volume center, with some local surgeons recommending that patients choose a particular hospital, which happened to be a low-volume center. Most patients, regardless of where they chose treatment, listened to the advice of trusted individuals and made a treatment choice based on that valued information. The recommendation from the trusted source (e.g., a surgeon) appeared to be a main driver for whether patients traveled to a

low- or high-volume center. No patients reported getting a second opinion.

Most individuals who did not mention having a recommendation from a trusted source noted that aspects such as personal experience with, or prior knowledge of, the surgeon or hospital, as well as familiarity with others who were treated by specific surgeons or hospitals, were important to choosing where to go for treatment. This was especially notable for patients who chose low-volume centers. Reasons for this may be that in the absence of surgeon recommendations, patients rely on personal experience and familiar social networks to help them choose a treatment center. This may have resulted in patients choosing low-volume centers over higher volume centers due to possible comfort and familiarity of their social networks with lower volume centers. If surgeons had recommended a high-volume center for treatment, they may not have relied on the socially available and familiar knowledge that led them to choose a low-volume center.

As anticipated, distance did play a role in the decisions of some rectal cancer patients living in a very rural state. However, it did not appear in most cases that patients choosing more local, lower volume centers did so because they could not access a higher volume center. Rather, they chose the nearer low-volume centers because they were recommended to them by a local physician or because they were just more familiar with local providers. This highlights the importance of referrals received from physicians who diagnose rectal cancer. The patients in our study conveyed that they trusted the referring physician to send them to the place where they would receive the best care. Our results also suggest that surgeons at high-volume centers should maintain effective communication and referral networks with local providers.

In general, our findings were consistent with the tenants of the TRA/TBP in that patients' attitudes toward receiving surgery from an experienced surgeon or high-volume hospital was a poor predictor of their actual behavior because almost all reported that having an experienced surgeon was important to them, but less than half received surgery at a high-volume hospital. A better predictor was their intention to assess surgeon experience or hospital volume and make a decision based on that information. Most who attempted to assess experience/volume through asking questions of the surgeons or researching surgeon reviews and expertise online received surgery at a high-volume hospital. Most who exclusively relied on physician referrals or personal experience were treated in low-volume facilities. The majority of these patients said they had a choice of surgeon and where to go, but almost all said they went where they were recommended because they trusted the referral.

Our findings were also generally consistent with a study of breast cancer patients that found the majority reported they were referred to their surgeon by another doctor.[25] This study also showed that those who selected a surgeon based on reputation were more likely to be treated by a high-volume surgeon in a NCI-designated cancer center, whereas those who relied on physician referral or selected a surgeon based on proximity were less likely to receive treatment in a NCI-designated cancer center.[25] However, about one-quarter of breast cancer patients reported selecting their surgeon based on reputation, whereas very few participants with rectal cancer reported selecting their surgeon based on reputation. This difference could be related to the higher socioeconomic status of breast cancer patients compared to rectal cancer patients, or to the more socially acceptable discussion of breast cancer compared to rectal cancer.[35]

Limitations

Due to patients and providers originating from a single state, our findings may not generalize to other states or regions of the USA. However, patients were recruited from a population-based registry, which enhances the representativeness of study participants. Study findings will be used to develop a questionnaire that we plan to field in a number of other states to assess potential differences between states and/or regions. Secondly, time since diagnosis varied from 1 to 3 years among patients. This variation may have led to differential recall of decision-making processes. However, a study conducted among Iowa breast cancer patients over age 65 diagnosed between 1999 and 2001 did not report a difference in ability to recall treatment information by time since diagnosis.[36] Finally, the study was based on interview data, and therefore, findings were derived from patient accounts of their decision-making processes. The intent of this qualitative study was to elicit a range of beliefs, attitudes, and behaviors that can explain variation as to where patients with rectal cancer receive treatment.

Conclusion

Our sample of Iowans previously diagnosed with rectal cancer generally relied on referrals, recommendations, personal experience, and characterized surgeon experience based on more subjective assessments including interpersonal skills, ability to explain the procedure, and perceived confidence of the surgeon. While almost all patients indicated that surgeon experience was important, most did not attempt to objectively assess surgeon experience. Whether patients simply assume surgeons are experienced, or are reluctant to ask surgeons about their experience, it is possible that if they knew that Dr. X located 10 miles away performed 5 rectal cancer resections in the last year, and Dr. Y located 30 miles away performed 50 rectal cancer resections in the last year, they would

decide to travel further to Dr. Y. Further research is needed to determine rectal cancer patients' preferences for seeking out information about surgeon/hospital volume and experience, since our findings suggest they may not be comfortable with directly asking the surgeon, nor with relying on Internet-based information. Once these preferences are determined, patient education campaigns, decision support tools, patient navigation programs,[37] and patient activation interventions[38,39] could be tested among rectal cancer patients to help them make decisions about where to receive treatment.

It is also important to determine the factors that drive referrals for rectal cancer patients. There are many potentially important factors that referring physicians (typically primary care physicians or diagnosing gastroenterologists) are simply not aware of because they are not professionally involved in the treatment of rectal cancer, only with diagnosis and referral. These factors include the volume-outcome relationship in rectal cancer; the need for multidisciplinary treatment that affects staging, neoadjuvant chemoradiation, and surgery; and the widely proven superior outcomes after total mesorectal excision, which is a surgical approach that has never been part of general surgery graduation requirements. Lack of awareness of these factors may be perpetuating the basing of referral decisions on professional relationships with surgeons rather than on expertise. Physician education interventions may therefore be beneficial. However, such interventions will come with challenges. Accountable Care Organizations (ACOs) have the potential to facilitate education and changes in referral patterns to achieve quality care improvements that could lead to shared savings. The shared savings model could provide the business case for participating gastroenterologists to refer rectal cancer patients to the most experienced surgeons. A similar business case would exist for small hospitals that participate in ACOs with larger hospitals.

Author's Contribution Dr. Charlton was involved in every aspect of the study and developed the initial manuscript draft. Drs. Mengeling, Chrischilles, Lynch and Ward participated in the conception and design of the work. Ms. Shahnazi and Hunter were central to the acquisition and analysis of the data. Drs. Gribovskaja-Rupp, Mengeling, Chrischilles, Lynch and Ward contributed to the interpretation of the data. All authors provided multiple rounds of critical review and revisions, reviewed the final version of the manuscript, and approved it for submission. All authors have agreed to be accountable for all aspects of the work.

Compliance with Ethical Standards

This study was approved by the University of Iowa Institutional Review Board.

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