

BMJ Open 'Because Everybody is so Different': a qualitative analysis of the lived experiences and information needs of rectal cancer survivors

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To cite: Saunders CH, Goldwag JL, Read JT, *et al.* 'Because Everybody is so Different': a qualitative analysis of the lived experiences and information needs of rectal cancer survivors. *BMJ Open* 2021;**11**:e043245. doi:10.1136/bmjopen-2020-043245

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2020-043245>).

Received 29 July 2020
Revised 08 March 2021
Accepted 22 April 2021



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ABSTRACT

Objective To (1) characterise (A) the lived experiences and (B) information needs of patients with rectal cancer; and (2) compare to the perceived lived experiences and information needs of colorectal surgeons.

Design We conducted 1-hour semistructured qualitative interviews, dual independent transcript coding and thematic analysis.

Setting/participants Interviews included rectal cancer survivors (stages I–III), some accompanied by caregivers, at Dartmouth-Hitchcock Medical Center and experienced colorectal surgeons.

Results We performed 25 interviews involving 30 participants, including 15 patients with 5 caregivers, plus 10 physicians. Two major themes emerged. First, patients reported major impacts on their lives following rectal cancer, including on their everyday lives and leisure activities; identity, self-confidence and intimacy; mental health, especially anxiety. These impacts were mediated by their medical experiences, lifestyle and attitudes. Second, the diversity of effects on patients' lives means that care, counselling and information needs should be personalised for a better medical experience and outcomes. Surgeons did not report knowledge of the full range of patient experiences and reported limited counselling in key areas, particularly concerning intimacy and mental health.

Conclusion Rectal cancer diagnosis, treatment and survivorship dramatically affect all people, regardless of which surgical treatment they undergo. Effects are varied and necessitate customised care, counselling and information, which surgeons are not currently providing. Because rectal cancer affects every part of patients' lives, they need holistic support and information. Patients would benefit from substantial support after treatment as they establish a new normal.

INTRODUCTION

Although around 45 000 people face a new diagnosis of rectal cancer annually in the USA,¹ there are gaps in our knowledge of their lived experiences during diagnosis, treatment and into survivorship. Major surgery is the primary treatment for rectal cancer, including removal of the cancer with either

Strengths and limitations of this study

- Semistructured interviews performed with rectal cancer survivors about their lived experiences regarding their cancer care.
- Semistructured interviews were also performed with colorectal surgeons about their practice patterns.
- Interviews were dual independently coded.
- Thematic analysis was performed and themes were identified and member checked.
- Results are from the perspective of rectal cancer survivors and may not be generalisable to all patients undergoing rectal cancer treatment.

reconstruction and reattachment of their bowel to the remaining rectum (low anterior resection (LAR)) or removal of the end of their colon, rectum and anus and creation of a permanent colostomy (abdominoperineal resection (APR)).² Both treatment options have major impacts on patients' day-to-day lives.^{3–5} Either surgical choice represents a major life event for patients, possibly including additional chemotherapy and/or radiation therapy before or after surgery.²

While researchers have done qualitative studies of rectal cancer survivors' experiences, most narrowly focus on single domains.⁶ Broad explorations of colorectal cancer survivors' lived experiences are limited to Taiwanese and English contexts.^{7 8} Similarly, patient-reported outcome measure studies provide discrete snapshots of moments in patients' lives at the time of queries.^{3 8} Patient's information needs relative to their experiences are also underexplored. One international survey explored—in binary fashion—whether patients felt their information needs were met in certain domains.⁹ And a scoping review found most studies of colorectal cancer needs did not include patient perspective.¹⁰ A comprehensive picture of patients' lived

experiences and related information needs during survivorship is missing from the literature.

Given these research gaps, we aimed to characterise rectal cancer survivors' lived experiences and information needs. We also compare their experiences and stated information needs to the perspectives of experienced rectal cancer surgeons.

METHODS

Design

In support of our efforts to develop an informational tool for patients with rectal cancer, in this qualitative study, we aimed to:

1. Characterise the (A) lived experiences and (B) information needs of patients with rectal cancer during diagnosis, treatment and survivorship.
2. Compare patient-reported experiences and information needs to those of rectal cancer surgeons, identifying potential gaps in surgeon knowledge.

We used a thematic analysis approach.¹¹⁻¹³

Reporting

We reported our results using the Consolidated Criteria for Reporting Qualitative Research (online supplemental appendix 1).¹⁴

Data collection

Eligibility and screening

Patients and caregivers

All willing rectal cancer survivors who had completed treatment for non-metastatic rectal cancer at Dartmouth-Hitchcock Medical Center, who were 18 years or older and spoke English were eligible for inclusion. Survivors had to have undergone with LAR or APR.

We identified eligible patients through chart review, purposively sampling by age, sex, socioeconomic status, surgery type and patient-reported outcome scores for bowel function (COREFO - Colorectal Functional Outcome Questionnaire)¹⁵ and mental health quality of life scores (PROMIS Global Health - Patient-Reported Outcomes Measurement Information System Global-10).¹⁶ Caregivers were included if requested by the patient and were interviewed at the same time as the patient.

Surgeons

US-based board-certified colorectal surgeons who care for patients with rectal cancer were eligible for inclusion. Surgeons had to have performed at least 15 rectal cancer operations in the last year including at least one LAR/reconstruction and one APR/colostomy.

Recruitment and consent

Patients and caregivers

SJI, a male surgeon and health services researcher, called each participant to introduce them to our study and our aims. In most cases, he was the surgeon who performed their procedures, so they had existing personal relationships. SJI assured patients that their participation was

completely voluntary. When they hesitated, he politely disengaged. We assigned each participant a unique number.

Surgeons

For surgeon participants, we identified participants through the American Society of Colon and Rectal Surgeons (ASCRS). Participants were selected purposively based on years of experience, location of practice in the USA and practice type. SJI introduced participants to the study through personal communication.

Procedures-interviewers

Patients and caregivers

We developed and piloted an interview guide (online supplemental appendix 2) with a patient partner (AB) and among our research colleagues. The guide contained open-ended questions about patients' lived experiences, which we followed up with various probes based on where the conversation flowed. Some probes are detailed in the interview guide; others were impromptu. This lived experience content comprised the variety of the interviews.

CHS conducted most interviews, supported by JLG. CHS is female and has a PhD in Health Services Research and an MPH. She is experienced in qualitative research with vulnerable groups. JLG, also female, is an MD and surgical trainee with experience with qualitative research and care of vulnerable patients. In cases where JLG had previously cared for eligible participants, CHS performed the interviews, so we did not have pre-existing relationships. In one case, CHS had interviewed a caregiver and patient pair previously.

MAD trained JLG in conducting qualitative patient-facing interviews and reviewed the first transcripts of each interviewer. We assured all participants of confidentiality and labelled them with numeric codes, not names. We also stored our data in a locked file cabinet.

Surgeons

We also developed and piloted a surgeon interview guide among our research colleagues and with a colorectal surgeon (online supplemental appendix 3). JLG conducted all surgeon interviews via telephone.

Consent and interview procedures

Patients and caregivers

ST, the scheduler for SJI, called each participant to schedule an appointment after they expressed verbal interest in participation. CHS or JLG met participants in the hospital lobby and walked them to a private interview space, stocked with refreshments. Interviewers presented participants with a study consent sheet, explained motivation for the research, answered participant questions and obtained documentation of informed consent before proceeding.

We audio recorded all interviews and transcribed them verbatim. We discussed data saturation as interviews progressed, taking memos as needed, and paused interviews when we agreed had reached saturation and no new

major themes emerged.⁴⁻⁶ We did not offer repeat interview opportunities or return transcripts to participants for review.

Surgeons

JLG scheduled mutually convenient phone interview times with surgeons. She verbally consented them to participate over the phone and audio recorded conversations.

Data analysis

We performed inductive thematic analysis informed by Braun and Clarke. After familiarising ourselves with the data by reading transcripts (step 1), JLG, SJI and JTR coded the data line by line for patient and caregiver interviews (step 2), using memos as appropriate and consulting with CHS. JLG and JTR coded all surgeon interviews using ATLAS.ti software. JTR is a male student researcher studying medicine and with a Bachelor's Degree in Decision Science. We coded a subset of transcripts to develop a shared codebook. We iteratively repeated this process until our codebook was relatively stable, then we coded the remainder of the data. Our codebooks are described in detail in online supplemental appendices 4 and 5.¹¹⁻¹³

A multidisciplinary analysis team, including CHS, JLG, JTR and SJI, discussed initial themes. Each coder reviewed the data and brought draft themes to our meeting (step 3). We then justified themes from each primary coder, developing a shared set of themes (step 4). Then, each coder re-reviewed the data to confirm that the themes matched our own understanding of the data, with particular attention to code occurrences. We shared our overall themes with all patient and surgeon participants (member checking). After finalising our themes, we developed a visual representation of our findings, which we shared with participants for feedback, along with a brief description of our findings (figure 1) (step 5). Finally, we wrote up our results in a report, which is represented in this manuscript (step 6).

RESULTS

Participants

We interviewed 30 participants in 25 interviews: 15 patients (7 LAR, 8 APR) with 5 caregivers and 10 surgeons. There were seven female patients with nine patients under 65 years old. Nineteen participants had high school degrees or above, six had college and/or advanced degrees. Health literacy was determined to be highest or high for 14 of patients and four caregivers. The median annual income for patient participants was \$60 000 (IQR: 29 000–97 500). This is consistent with median income in Northern New England, which ranges from \$57 918 (Maine) to \$76 768 (New Hampshire) (table 1).

Interviews occurred during spring 2019. One patient declined to participate. Patient interviews lasted between 41 and 93 min (median 61). Surgeon interviews lasted between 25 and 59 min (median 35). Demographics reflected those of Northern New England.¹⁷

Themes

Two major themes emerged from our analysis (figure 1, table 2):

Major theme 1: all rectal cancer survivors experienced major—but varied—impacts on their lives.

Major theme 2: varying experiences of patients with rectal cancer correspond to various information needs.

Major themes appeared repeatedly and were important in our data. Minor themes occurred less frequently, but were notable to the researcher team.

Major theme 1: all participants experienced major—but varied—impacts on their lives

The most salient theme was that all patients and caregivers are profoundly impacted by their experience with rectal cancer from diagnosis to surgical treatment decision-making and beyond. One participant (APR-19) summed up the magnitude of the decision facing patients: 'It's

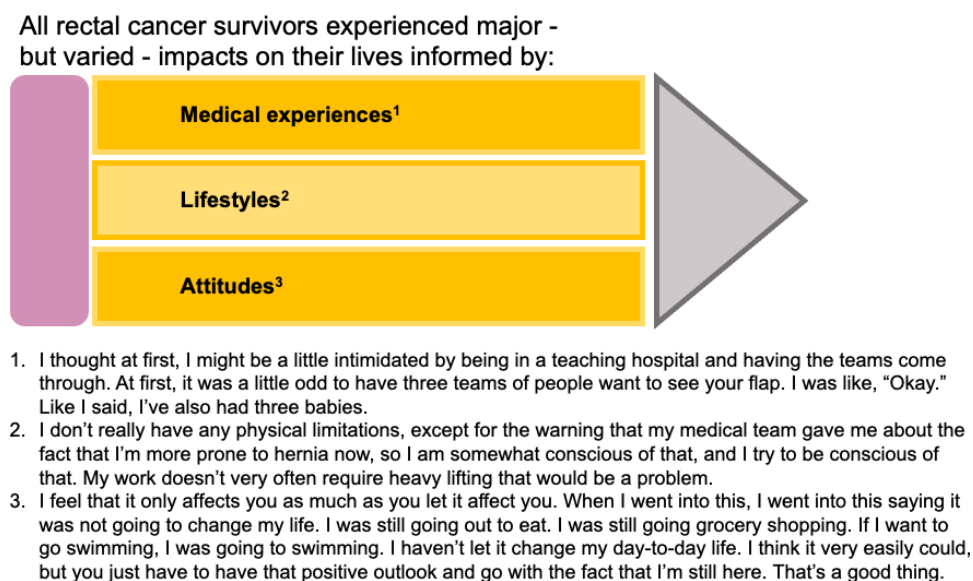


Figure 1 Major emergent themes.

Table 1 Demographic characteristics of consented participants

	Patients		
	Reconstruction (LAR) n=8	Colostomy (APR) n=7	Caregivers (n=5)
Race			
White	6	7	5
Other/Prefer not to say	2	0	0
Ethnicity			
Not Hispanic	7	7	5
Other/Prefer not to say	0	1	0
Education			
No high school	1	0	0
High school degree	2	4	3
Some college	2	1	1
4-year degree	2	2	1
Master's degree	0	1	0
Health literacy*			
Highest	4	6	1
High	2	2	3
Low	1	0	1
Insurance			
Private employer provided	3	4	2
Provide self-pay	1	2	1
Medicare	1	2	1
Medicaid	2	0	0
None			
Income (median (min-max))	\$65 000 (16 800–150 000)	\$50 000 (13 300–200 000)	\$47 900 (23 000–150 000)

*Health literacy assessed with Chew's Single-Item Health Literacy Screener,^{34 35} which reads, 'How comfortable are you completing medical forms by yourself?' 'Extremely' represents highest health literacy above, 'quite a bit' represents high, 'somewhat' represents low and 'not at all' represents lowest.

APR, abdominoperineal resection; LAR, low anterior resection.

going to affect you for the rest of your life so you can't make [the surgical treatment decision] just lightly.'

Surgeon participants reinforced this finding, emphasising that rectal cancer affects patients at diagnosis, treatment and survivorship.

Everyday lives

Many participants noted rectal cancer interrupted their everyday lives and leisure activities. One (APR-9) said, 'I'm just scared of hiking and stuff like that, but that's something that I need to get over.' Patients worry about their appliances showing, or urgency issues interrupting everyday activities. One participant (LAR-14), who ultimately sought a LAR reversal, described how

all encompassing postsurgical life could be, especially concerning issues of urgency that kept her from her everyday life and the things that mattered most to her. She said:

Even though I was wearing Depends, I may not make it. There were days that I went through five Depends and it was just all from the rectum. I felt that I couldn't really go anywhere, do anything. Even coming [...] for my appointment, I would not eat or drink a thing from morning until whenever I got back home again because I just didn't want it shooting right through me. That's all I could think of, it would just shoot right through me.

APR-9 noted postsurgical disruption to his day-to-day life actually affected his ability to heat his home, noting:

I can't do the things that—a lot of the things that I used to do. We used to get out. We used to cut our own wood, split our own wood. I will still use the chainsaw, but I can't hold up the way I used to, because it starts pulling my stomach from the bending and everything like that, and then trying to lift the logs with planks, I just can't do it. We really can't afford to buy wood, and we only heat with wood.

Surgeons were also aware of these effects on day-to-day life, but discussed these issues only after prompting by interviewers. Asked about how they counselled patients about lifestyle, surgeons suggested they offered assurances. Surgeon 5 said vaguely, 'I'll tell them that there's nothing you can't do.'

Identity and intimacy

Other participants struggled with identity issues, regardless of which procedure they chose, struggling to rectify the people they were before rectal cancer and surgery with their postsurgical selves. APR-12 said, 'it's defining me in a way to people who don't know me in a way that I don't want to be defined.' An important part of this was feeling that others saw them differently; APR-9 said, 'I felt—what word can I use here? I guess I felt less human.'

Participant LAR-2, a man partnered with another man, struggled with issues of sexual identity after his anus was surgically altered. For LAR-1, erectile dysfunction after surgery came as a surprise. He noted:

The home life that I have right now, it's a little stressful but it has nothing to do with the cancer. However, certainly one thing that did happen was I have erectile dysfunction now. The sex life is less active. It's going at the same time where I'm getting older, your <adrenaline> may be a little bit different *laughter*. I certainly wish that was a little bit better. That was something I didn't count on. I should have but that was something I didn't quite understand. I'm sure I was told but I don't think I quite understood. The surgery itself I think first of all probably affected the nerves. It could be. You're down there where the surgery is.

Table 2 Representative quotes

Theme	Subtheme	Representative quotes	Participant No
Major impacts on...	Everyday lives	If I went to one of my grandkids' concert or play or any kind of a performance, I'd sit in the back row, so that I can make a quick exit to the restroom. I always even to this day carry a change of clothing with me and supplies.	LAR-14
		I really wish I could be more discreet with it but in some environments and clothing choices, it's frequently apparent to me that, yes, there's that. It's annoying to me.	APR-12
	Identity	They know Grandpa [...] went through some major surgery, and Grandpa [...] will never be like he used to be. So, yes, it's been a huge change.	APR-9
Varied impacts based on...	Intimacy	Intimacy is gone because I just am so afraid of—you don't realize beforehand how sensitive everything is in that region and how connected they really are until you go through it.	LAR-4
		I was informed that if they had to go and give me the butt bags [colostomy] that my sex life would be totally gone. It is. I really don't discuss this a lot, but that's life now. I've learned to deal with it.	APR-9
	Mental health	Sometimes you get depressed like, 'Is it ever going to get any better than this?' Or 'Am I actually getting better or am I actually getting worse or whatever?'	LAR-13
Lifestyle	Previous experience with the medical system	I thought at first, I might be a little intimidated by being in a teaching hospital and having the teams come through. At first, it was a little odd to have three teams of people want to see your flap. I was like, 'Okay.' Like I said, I've also had three babies.	APR-18
		It was an awful lot to deal with, I definitely have empathy for anybody that has to go through this process. Unfortunately, my first one [tumor] wasn't caught early enough not to have to go through all these treatments.	LAR-7
	At work	...a construction worker and he was like, 'I can't be needing to go to the bathroom when I'm really high up. This was the only choice for me because I needed that predictability.'	Surgeon 6
I don't really have any physical limitations, except for the warning that my medical team gave me about the fact that I'm more prone to hernia now, so I am somewhat conscious of that, and I try to be conscious of that. My work doesn't very often require heavy lifting that would be a problem.		APR-12	
At home	Pretty much outdoor stuff, but I really have to watch what I'm doing now, because I think I'm still protecting myself, because it slips and falls. I don't want to rip something or anything like that, but all I can do is smile and do what I can do.	APR-9	
Support at home	Yes, right from the very beginning. He was like, 'I just want you here. Whatever that means, we're going to do it because you have to be here.'	APR-18	
	We've got love from friends, love from strangers, love from everybody. If we hadn't had this love, he wouldn't be here.	LAR-3 caregiver	
Attitudes	I feel that it only affects you as much as you let it affect you. When I went into this, I went into this saying it was not going to change my life. I was still going out to eat. I was still going grocery shopping. If I want to go swimming, I was going to swimming. I haven't let it change my day-to-day life. I think it very easily could, but you just have to have that positive outlook and go with the fact that I'm still here. That's a good thing.	APR-5	
Personalised care and information			

APR, abdominoperineal resection; LAR, low anterior resection.

For some, in particular, female patients, self-confidence and intimacy were tightly related. Self-consciousness about their appliances or urgency associated with their rectal cancer surgery were impediments to intimacy with partners. LAR-4 noted how her intimate life changed after surgery:

It's the emotional journey, the physical journey. I'm sure for him, it's having to watch your spouse go through what they go through on a daily basis, trying to make it work. Intimacy is gone because I just am so afraid of—you don't realize beforehand how sensitive everything is in that region and how connected

they really are until you go through it and you start researching and people start talking to you about different things and you realize, 'Wow, I'm definitely not trying that because I'm not going through another perforation.' So there're a lot of changes in one's life that doesn't really get catered to as much as it should.

These participants also noted that they were not prepared for the disruption to their intimate lives after surgery. Participant LAR-4, when asked if she knew about potential intimacy issues after surgery, said she only understood in broad strokes:

No, not really. I mean the doctors will blanket-tell you things. The intimacy part no, but I had been having problems before the cancer and it was probably due to the cancer, I just didn't know about the cancer yet. So it kind of all tied together, but it's not really—for the doctors, I think they have a hard because they want to take care of the situation instead of encompassing the whole thing which really is...

Although she noted that she did not expect the surgeons to cover these types of intimacy issues, noting, 'for a surgeon especially, it's kind of out of their realm, if you think about it. They have a job to do, so they can't really be all-encompassing around the patient and working as an umbrella.'

Surgeons were not surprised by issues of intimacy, although they admitted they perhaps do not counsel appropriately on these issues. Surgeon 3, for instance, said, 'I probably don't do a very good [job explaining] the sexual risk associated for the men and women. [...] I don't—I mention it—but I don't—I wouldn't say I go into significant detail.' Identity and self-confidence were not mentioned by surgeons.

Mental health

Suicidal ideation and self-loathing were common among our interviewees but not frequently disclosed to surgeons. LAR-4 said, 'I was really dark. I hadn't started enemas and I really had some dark thoughts about suicide, to be honest, and I never...I never told anyone, so this is really the first time....' APR-9 noted that realising he no longer had an anus triggered a deep depressive episode, 'that threw me into a depression. Then after my visiting nurse did what she'd done, I still got to stay in bed all the time. I didn't want to talk to the kids, I didn't want to see anybody.'

General anxiety was another common experience. Patients reported carrying extra changes of clothes, scanning for the nearest bathroom and fearing leaving their homes for fear of embarrassment. Patient APR-5 said, 'I get embarrassed easily if my bag makes noises out in public' and many patients with ostomies reported fears of having their bags leak, malfunction or smell. Patients with LAR were chiefly concerned with having unplanned bowel movements. Patients often had plans should an accident occur, even after years of not having one. LAR-7 said, 'it's that fear of having an accident. If you're still working, at work—it's a very embarrassing thing, it never did happen to me in public but it certainly can.'

Mental health ramifications of rectal cancer were not mentioned by surgeons during interviews.

The experience of rectal cancer was varied based on participants' individual experiences

The extent to which rectal cancer impacted people's lives was mediated by their individual circumstances, including their experience with the medical system, their lifestyle and personal attitudes.

Previous experience with medical system

Experiences with the medical system coloured expectations and ultimately rectal cancer experience. APR-12 recalled:

That was the first of several blunders that the oncologist made in treating me. Eventually, I asked him about alternatives and we really had an awkward conversation where he was unwilling to offer any alternatives, and he really didn't understand what I was asking... He didn't listen well to me, and he did not read my chart before we had check-ups. For that reason, I got a second opinion...which was brilliant.

Lifestyle

Lifestyle was another mediating factor, including both work and personal life.

Work life

Patient LAR-1 reported his professional life was essentially unchanged. He recognised his privilege concerning making a living while recovering from rectal cancer treatment, saying:

I wish I had a little more energy but I'm perfectly functional at work. I've never missed a day of work since I've had this treatment. A part of it is that I'm fortunate. If you're a construction worker, if you had to do a lot of physical work, I think my answer would be quite a bit different.

Similarly, LAR-1 noted that despite issues of urgency, his work life was unchanged, 'I use the bathroom more than I used to. [...] Work, I haven't been caught. Work, <sure>, knowing that I can leave if I need to. I've done that before.'

For those with less flexibility at work, usually those with lower socioeconomic status, however, the impacts of treatment were more dire. A patient who worked seasonally (LAR-2) noted that he had to collect state disability payments and, 'I did work, but it was not [full-time]. I had to work part-time.' One participant (LAR-4) lost her job. Those who underwent APR and had a permanent colostomy often continued working, even in physically demanding jobs.

Home life

Patients were motivated throughout their recoveries by trying to reattain the life they had before cancer. Many patients' lives were changed because they no longer felt confident enough to be in public at all, 'I think that my self-consciousness about the size of the hernia keeps me from going out probably very much, so I get more isolated' (APR-15). Patients would regulate their diet in dramatic ways as a means of controlling their bowel movements. One patient talked about not eating at all before regular public outings to control bowels and minimise anxiety, LAR-14 said, 'I would not eat or drink a thing from morning until whenever I got back home

again because I just didn't want it shooting right through me. That's all I could think of.' Past activities that she was currently unable to do were a source of regret for patient LAR-14. After realising she could not attend her grandson's baseball games and birthday parties, LAR-14 decided to reverse her reconstruction and return to an ostomy.

Support at home

Similarly, support at home influenced patient resilience after rectal cancer surgery, for both reconstruction and permanent colostomy. A patient (APR-12) with a permanent colostomy noted his family helped him get back to feeling normal, 'My immediate family is small, and they understand everything I went through. I really have no issue with home life as compared to before my surgery.' A caregiver (LAR-10–11) noted she pushed and encouraged her partner to participate in things that brought him happiness, like going out to eat, even when he had concerns about bowel function:

Your mind is very strong [Laughter]. It's stronger than people think. So, our biggest thing has been if he's had a bad day, I'm like, 'Let's go to dinner.' He'll be like, 'Ugh,' and he stresses out about it or, 'I want to go to this person's house,' and he'll be like, [caregiver name]. And I'll be like, 'Come on, let's go.' Then, we go and he's fine but he's constantly thinking about it and I'm thinking about it but you can also tell that he's relaxed a little bit once we get there.

When patients were less supported at home, however, recovery and a return to normalcy were more challenging. LAR-4 said:

So my poor husband in this whole time, he almost lost me on the table, to begin with. That was a very close call, and then to see me sit and wait and watch and watch my job, cut my hours, because now I'm at work and I'm in the bathroom a lot, so they cut my hours because of that, but he kind of has taken a tail-spin. He will never say it. He's upped his drinking... but he's had a hard time of it and I'm trying to help him.

Attitudes

Patients' personal attitudes about illness, treatment and recovery also affected their recovery. Those who maintained positive or hopeful attitudes were strengthened by them. Some drew on their faith or spirituality, encapsulated by this exchange between a patient (LAR-2) and a partner (LAR-3):

Partner: Have faith.

Patient: Just be—yes, have faith.

Partner: Have faith, believe.

Patient: Believe everything's going to be okay.

Others relied on self-motivation or positive thinking. Patient APR-5 said, 'I feel that it only affects you as much as you let it affect you. [...] I haven't let it change my day-to-day life.'

Some patients vacillated between positive and negative thinking, reflecting on the power of positive attitudes only after periods of more negative thinking. In particular, one patient APR-9 stated, 'One morning, I sat up on the bed, sat on the bed, and I said, "Okay, you gotta pull yourself out of this, and just swift kick in the ass, start doing things." I started doing things.'

Although surgeons appreciated that patients' individual circumstances affected their treatment and recovery, they were more likely to attribute these to treatment-related circumstances and not have means to address these directly.

Major theme 2: varying experiences correspond to various information needs

Patients' varying experiences correspond to differing information needs, but there are baseline needs that most patients with rectal cancer share. In particular, patients wanted simple, easily understandable and accessible information. One patient (LAR-1) said materials should be, 'as simple as possible and don't put too much information out there. [...] Let the [links for more information] guide you.' Some interpreted this patient-friendly presentation of information with specific suggestions, like bold lettering, big font sizes, clearly labelled sections and bullet points.

Participants also noted how their needs and their partners' needs changed throughout their experience with rectal cancer. One patient (APR-18) said, 'not everybody's going to be the same stage.' A caregiver (LAR-3) noted that the information should span changing needs across the rectal cancer journey, 'Yes. There needs to be like a research button, a practical button, a resources button.' and 'There's got to be a pain button, there's got to be like when you first get diagnosed, after you're diagnosed.'

Minor themes

Minor theme 1: participants' caregivers were affected, too

We found rectal cancer diagnosis, treatment and recovery also affected caregivers. One caregiver discussed the importance of caring for themselves, 'I had to start some self-care stuff to be able to care for him and the caregiver needs to know that' (LAR-2–3). Caregivers experienced strong feelings as their loved ones went through treatment, including fear, regret, pride and admiration. They also reported rectal cancer changed the dynamics of their relationships with their loved ones. The patient (APR-18) said:

I think for me the biggest impact was on my family seeing me in a different role and my kids feeling like they needed to be around a little bit more, or needed to be careful of me somehow, or take care of me. I'm the caretaker, so that was emotionally the harder part.



Minor theme 2: some, but not all, surgeons felt responsible for helping patients navigate lifestyle issues

Additionally, surgeons had differential feelings of responsibility concerning patients' lifestyle issues. Surgeons who had access to resources like enterostomal therapists (nurses specifically caring for ostomies) were likely to use them and rely on them to provide information and support to patients. Surgeon 4 said, 'we rely heavily actually on [...] enterostomal therapists both for just knowing what appliances and helping people get the right appliance and also their emotional support.'

Minor theme 3: surgeons reported sexual function counselling as an area for improvement

Surgeons reported different levels of counselling regarding sexual dysfunction, and identified it as an area for improvement. Surgeon 10 said, 'I do think we don't talk about sexual function enough, particularly in women.'

Member checking

We shared our overall themes with all patient and surgeon participants. Two of 20 patients and caregivers and 5 of 10 surgeons responded and agreed that the major themes we presented were representative of their experiences and sentiments.

DISCUSSION

Summary of findings

We found survivors of rectal cancer experienced profound impacts on nearly every aspect of their lives, varied by their experiences with the medical system, their lifestyles and attitudes. These results are novel in capturing the comprehensive picture of survivorship after rectal cancer.

These major impacts of rectal cancer treatment on patients' lives occurred particularly during survivorship. Identity and intimacy were of particular concern, which contributed to major disturbances in mental health and anxiety—including suicidal ideation and severe self-loathing. Participants also voiced concerns in home life and work life that stem from sequelae of rectal cancer treatment, particularly surgery. Those who had flexibility with work and support at home were more likely to voice a greater success at regaining some normalcy.

Bowel function (LAR) and ostomy issues (APR) dominate their lives as survivors. Participants noted a need to adapt their lives to accommodate this. Participants with an LAR noted the need for dietary changes, abstinence from eating prior to social outings and even social isolation in extreme cases. Participants with an APR noted changes to their lives to address anxiety of uncontrollable bowel noises or fears of having their bags leak, malfunction or smell. The effect on day-to-day life again varied based on lifestyles and attitudes.

Favourable factors for participant success in survivorship were the importance of a positive attitude, family/caregiver support and faith/spirituality. Given their

varying experiences, participants reported the need for clear, simple information about rectal cancer treatment and survivorship, with options to explore topics in more detail depending on their own information preferences.

Rectal cancer surgeons recognised that these effects exist for patients facing rectal cancer and in survivorship. Although surgeons were aware of these common issues, many did not offer counselling concerning them. Much of this has to do with limited time, resources and expertise. For patients undergoing treatment for rectal cancer, surgeons spend the majority of clinic time counselling patients on technical aspects and choices of treatment. During survivorship, surgeons were more likely to focus on the treatment impact on bowel function rather than lifestyle. If surgeons do discuss lifestyle, they typically use reassurance alone. Moreover, surgeons rarely address many issues related to mental health.

Results in context

Researchers have previously explored discrete elements of patients' experience after rectal cancer treatment, like appliance management,¹⁸ physical activity¹⁹ and sexual health.^{20 21 4 8 9 22 23} They have also explored the experiences of patients after specific treatment pathways, like stoma reversal,²⁴ or sphincter-saving surgery.²⁵ A meta-synthesis of qualitative studies from Rutherford and colleagues included 15 studies, all but two of which narrowly focused on one area of patient experience.⁶ The two studies focused on holistic experience were in Taiwan and England.⁶ Both studies found major impacts on lived experiences, consistent with our findings.^{7 8} The novelty of our work is in the in-depth characterisation of the holistic experience of rectal cancer survivors in a US environment that is also rural. Our findings are consistent with those of the Macmillan ColoREctal Wellbeing Cohort Study, which found psychosocial factors, specifically self-efficacy and depression, relate to quality of life after colorectal surgery and that patients have low confidence in their own abilities to manage their illnesses.^{26 27}

Notably, religion and spirituality were not dominant themes in our research, despite their recurrence in cancer and colorectal cancer studies.^{28 29} This may be reflective of the population of study. Northern New England is among the least religious populations in the USA.³⁰

We also offer a more detailed perspective on patients' information needs. We know from Dau and colleagues' survey work that patients with rectal cancer often have unmet psychosocial needs, specifically in the workplace, and concerning mental health, sexual function and nutrition/diet.⁹ Additionally, Kang and colleagues found patients with rectal cancer are generally disappointed in commercially available patient education materials.³¹ Coupled with the knowledge from this study, we recognise the need to develop educational tools and support for patients during rectal cancer treatment and survivorship.

Additionally, this is the only assessment that compares patient experiences and surgeon perspectives on issues of treatment and survivorship.

Strengths and limitations

Our qualitative approach was rigorous using established techniques for thematic analysis and reporting in health services research.^{11–13} Additionally, comparing the perspectives of both patients with those of experienced rectal cancer surgeons is a strength.

Our research has limitations. Our sample reflects the perspectives of socioeconomically diverse patients with rectal cancer in rural Northern New England; our results may not fully generalise beyond that population.¹⁷ Racial disparities in colorectal cancer care are well established, and a future study could characterise the lived experiences and information needs of patients with rectal cancer of more racially and ethnically diverse backgrounds.³²

Additionally, as we made a choice to interview survivors of rectal cancer at one point in time, recall bias may have affected their retelling of their treatment journeys. By design, we also only capture their perspective at that time, not longitudinally. More in-depth, longitudinal interviews may add value to a future study. Additionally, patients who have survived rectal cancer may have different needs and experiences than those currently undergoing rectal cancer treatment and those who ultimately die from the disease.

Selection and social desirability bias are also a concern for both patient and surgeon interviews, given SJI reached out directly to each participant for recruitment. He was their surgeon and may have influenced their decision to participate. And even though they were assured of confidentiality, they may have been less forthcoming given their surgeon was involved in the study. Additionally, this may have meant the included participant experiences were largely similar. Similarly, the surgeon participants were colleagues of SJI, which may have influenced both their decision to participate and their answers.

Future research and implications

We aimed to conduct these interviews as a needs assessment aims to inform the future creation of patient educational tools including decision aids for patients facing rectal cancer. It became clear to us that there is no one-size-fits-all solution for information needs of patients with rectal cancer. Specific tools such as treatment decision aids alone will not address all of these patients' needs. Instead, there is a need for a comprehensive and personalisable set of patient education tools that address and support patients facing all three stages of rectal cancer: diagnosis, treatment and survivorship.

Another important implication of this study is that patients, caregivers and their surgeons are somewhat misaligned in how they perceive the experience of rectal cancer diagnosis and treatment. Both patient and surgeon education will be essential for improving our ability to meet the needs of patients with rectal cancer. Any tool will have to be based on patients' lived experiences, needs and desires. Armed with knowledge of what patients with rectal cancer want, we plan to develop a set of comprehensive patient education tools that is coproduced with

patients, caregivers and rectal cancer practitioners. It may be that patients need broader psychosocial support, beyond the remit of the clinical environment and that clinical teams need help identifying those patients who need to be connected to other services, including religious and spiritual supports, if they are available. There is already an appetite here, including extensive survivorship care guidelines from the American Cancer Society.³³

CONCLUSION

Rectal cancer diagnosis, treatment and recovery affect almost every aspect of patients'—and caregivers—daily lives. The magnitude of this effect warrants care and information that is broad, deep and tailored to patients' individual needs.

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Acknowledgements The authors thank the participants in this study, the patients and their families for so generously spending their time sharing their experiences with us. They also acknowledge Sandra Tsimis for her assistance in scheduling the interviews.

Contributors All authors (CHS, JLG, JTR, MAD, GE, SJI) contributed to the design and implementation of the research, to the analysis of the results and to the writing of the manuscript.

Funding This research is supported through an American Cancer Society Research Grant (IRG-16-191-33) and the Hitchcock Foundation. CHS' development of this manuscript was supported by the National Institutes of Health's (NIH) T32 Research Fellowship in Geriatric Mental Health Services Research (T32 MH19132; Bruce).

Competing interests CHS reports holding copyright in the considerATE suite, including the considerATE talk guide and the considerATE questions, tools to support care of seriously ill people. MAD reports fees from EBSCO Health and ACCESS Community Health Network and reports holding copyright in considerATE. GE reports royalties from Oxford University Press and Radcliffe Press, ownership of &THINK, SharpNetwork, and fees from ACCESS Community Health Network, Chicago Federally Qualified Medical Centers, EBSCO Health, Bind Insurance, PatientWisdom and Abridge AI. He also reports holding copyright in collaboRATE, integrate and considerATE.

Patient consent for publication Not required.

Ethics approval Dartmouth-Hitchcock Health Human Research Protection Program (DHH-IRB) approved this study (study 00030749).

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request. All data relevant to the study are included in the article or uploaded as supplementary information. Full deidentified transcripts are available upon request.

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