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It's not fine: A photo-elicitation study of rectal cancer survivors' emotions and coping strategies

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Abstract

Background: Comprehensive cancer care includes supporting the psychological health of survivors who are at high risk of distress. However, little is known about the emotional experiences of rectal cancer survivors specifically. We sought to explore psychological well-being and coping strategies utilized by rectal cancer survivors.

Methods: Twenty rectal cancer survivors shared photographs of their post-treatment experiences. In follow-up interviews, participants discussed photographs' meanings and emotional experiences during their cancer journey. Transcribed interviews were analyzed using iterative steps of inductive thematic analysis.

Results: Emotions ranged from sadness to anxiety and fear of cancer recurrence. Coping mechanisms were grouped into 3 categories: (1) seeking support and information; (2) focus on attitudes and perspectives; and (3) distancing strategies.

Conclusion: Our results highlight the persistent psychological impact of rectal cancer and need for additional support for survivors. Providers may help temper patients' fear of recurrence by explicitly discussing prognosis and risk of recurrence. Although multidisciplinary survivorship clinics are ideal, all cancer care providers and primary care physicians should feel empowered to screen for psychological distress and refer patients to appropriate resources when needed.

Introduction

The cancer care paradigm is shifting from acute illness to chronic disease requiring ongoing care and acknowledgement of an individual's journey from patient to survivor.¹ Psychological care is a particularly important part of survivorship as prior work shows higher levels of distress among cancer survivors compared with the general public even

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Supplementary materials

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Conflict of interest/Disclosure

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years out from diagnosis and treatment.²⁻⁵ The types of coping strategies (ie, avoidance and denial versus reappraisal and acceptance) used by survivors to manage distress have also been shown to be predictive of psychological symptoms, suboptimal well-being, and poorer health-related quality of life.⁶ Although these overall features are common across cancer survivors, the prevalence and intensity of psychological symptoms, coping strategies used, and long-term patient outcomes vary by cancer type and severity.^{7,8}

Distress is highly prevalent among colorectal cancer survivors, yet very little empiric evidence exists describing how such patients cope with their diagnosis and treatment.⁹⁻¹³ Of the 2 studies examining coping among colorectal cancer survivors, neither focus on rectal cancer specifically. Furthermore, the cohorts are not well-represented by rectal cancer survivors, and patients who received chemotherapy and radiation or those with permanent ostomies are not included.^{12,13} Notably, despite being frequently combined in research studies, rectal cancer patients differ considerably from those with colon cancer in regards to treatment plans and ongoing post-therapy needs.¹⁴ Compared with patients with colon cancer, patients with rectal cancer are more likely to report unmet post-treatment needs with 90% reporting at least one unmet need and more than half reporting unmet emotional needs.^{15,16} Another group found that after bowel and ostomy management, psychosocial impacts were the most commonly reported challenges, particularly among patients with temporary (41%) and permanent (48%) ostomies.¹⁷ Beyond this, however, little is known about the long-term psychological impacts and coping strategies employed by rectal cancer survivors.

In this context, we sought to explore psychological well-being and coping strategies utilized by rectal cancer survivors. By deepening our understanding of psychological health after rectal cancer diagnosis and treatment, we hope to inform future efforts focused on improving survivorship care.

Methods

Study design

Our team used a qualitative study to understand rectal cancer survivor psychosocial well-being and coping strategies.¹⁸ To do so, we utilized photo-elicitation, a novel approach consisting of the analysis of patient-submitted photographs combined with interviews. The use of photographs is a novel way of enhancing the understanding of what certain experiences mean to participants by uncovering deep emotions, memories, and ideas.¹⁹ The unstructured format and process of having participants provide their own images gives them the ability to discuss what they would like in the interview, which is particularly useful when there might be reluctance to talk about embarrassing topics. The photographs, then, help to overcome barriers and facilitate conversation, providing nuanced information on the illness experience while also providing anonymity and distance from sensitive issues.²⁰ The process is inductive, with data collected and analyses grounded in what participants chose to share rather than being based on responses to fixed interview questions.¹⁹⁻²³

This study is reported according to the Journal Article Reporting Standards by the American Psychological Association.²⁴ The University of Michigan Medicine Institutional Review

Board (HUM00178137) deemed this study exempt from continuing review. This study was performed in accordance with the Declaration of Helsinki.

Interview participants

Participants were recruited by convenience sampling using a Multidisciplinary Colorectal Cancer clinical registry, which encompasses all patients seen at our clinic. Inclusion criteria were intentionally broad to increase patient diversity and included: (1) 18 years old; (2) valid e-mail address; (3) access to a smartphone; (4) underwent curative-intent rectal cancer surgery; and (5) demonstrated no metastases or recurrence. Participants received \$50 for their participation.

Data collection

Participants were asked to share up to 10 photos that reflected aspects of their rectal cancer journey. Twenty rectal cancer survivors shared photographs of their post-treatment experiences and then underwent a minimally structured interview centered around the review of their photographs (Supplement S1). An anthropologist (C.A.V.), with experience in qualitative interviewing and no prior relationships to study participants, conducted the patient interviews either over the phone or via Zoom. Interviews were conducted between September 2020 and February 2021 and lasted 30–60 minutes. Interviews were audio-recorded, deidentified, and transcribed verbatim. Interviews continued until thematic saturation was reached (ie, infrequent emergence of new themes and code definitions remained stable).²⁵

Data analysis

Interview transcripts were coded utilizing the iterative steps informed by inductive thematic analysis.²⁶ First, several team members independently reviewed and annotated 2 to 3 transcripts. Each coder independently developed codes using open coding. Code definitions were then created to detail the contents of each code. Next, 2 members of the research team (S.J.R., C.A.V.) independently coded each transcript with meetings to revise the codebook and discuss discrepancies when necessary. Finally, a thematic schema was created by the entire research team. Research team members were selected to reflect diverse professional fields (eg, surgery, public health, anthropology) to increase trustworthiness. Preliminary findings were presented at a working group to investigate the clinical relevance of our identified concepts.²⁷ This group meets weekly and is attended by 5 to 10 surgeon researchers interested in using quantitative and qualitative approaches to exploring questions related to colorectal treatment and survivorship care. This was iterative, with several sessions dedicated to reviewing the themes and drawing from the groups collective clinical experiences. MAXQDA qualitative analysis software (VERBI software, Berlin, Germany) was used for coding.

Results

A total of 20 patients were included in this report (Table I). Participants were between the ages of 38 and 80 (mean 59.6). Biological sex was nearly even, with 45% male and 55% female. Most participants (95%) identified as white and non-Latinx. Most participants (80%)

had a low anterior resection and pathology of stage 0 or 1 (80%). Years postop ranged from 2 to >5.

Participants discussed their emotional responses when asked about their rectal cancer journey, which ranged from feelings of sadness during diagnosis and treatment to anxiety and fear around surveillance and the potential for recurrence. Throughout their experiences, participants used range of coping mechanisms, grouped into 3 categories: (1) seeking support and information; (2) focus on attitudes and perspectives; and (3) distancing strategies.

Emotional responses

Participants described a range of emotions which were experienced to differing extents during their diagnosis and treatment, management of late effects of treatment, navigation of social consequences of treatment, necessary surveillance, and the potential for recurrence (Table II). On hearing their diagnosis, some participants reported feeling sad or depressed, and experienced fears, including the possibility of death. As one participant described *when you hear the word 'cancer' you just fear the worst* (ID17). For some, these emotions continued after treatment as many patients struggled to navigate their symptoms (eg, clustering, frequency). Some patients with ostomies described particularly intense challenges including suicidal thoughts and decisional regret. One participant explained: *I don't know if I'd rather die than to have that. That's how bad I hated it. I was thinking, did I make the right choice? Because I don't know if I want to live with this the rest of my life* (ID18).

For others, there was a process of bereavement. Although some grieved a physical loss, for example, *loss of [a] rectum* (ID2), others grieved activities in which they were no longer able to participate after surgery. In other cases, participants described sadness due to the inability to control their bowels despite medication and dietary changes. In some instances, these feelings also impacted social aspects of their lives including connecting with friends, pursuing relationships, and maintaining their role as a caretaker. As one participant described, the *depression, it gets bad and it's very overwhelming for me* (ID13).

Participants also spoke of their anxiety and fear surrounding a potential recurrence, as one participant explained, *my biggest concern is, ... if cancer comes back, it's worse. And the other thing is that if it came back, I'm sure that I would have a permanent bag, and that just scares me to death* (ID15). Similarly, many reported frequently checking for signs of recurrence, such as bloody bowel movements and heightened anxiety surrounding surveillance appointments. Some patients described an increase in anxiety levels when surveillance became less intense:

My last colonoscopy, my gastroenterologist said, Okay, you can go 3 years now, instead of every year. And I thought, that's really good. As soon as I told my husband, as soon as I left, I mean, it was like panic attack. Like, oh, my gosh, 3 years, what can happen in 3 years? (ID8)

Overall, patients acknowledged their cancer experience as complex with one survivor summarizing, *I'd be stupid to say, oh, it's fine. No. It's not fine* (ID12). However, it is

important to note that although many participants described a process of moving through difficult emotions, not every participant described their experience in this way. Additionally, for some participants, it was difficult to isolate the cause of their response to their rectal cancer diagnosis and treatment alone, rather identified it as one of the many stressors influencing their well-being (eg, divorce, loss of a loved one, pre-existing condition).

Coping strategies

Patients employed multiple coping strategies (Table III), which can be considered in 3 major categories:

1. Seeking support and information: seeking social, religious, and informational support
2. Focus on attitudes and perspectives: focusing on the positive through reappraisal, rationalization, and humor
3. Distancing strategies: escaping one's circumstances by distraction, denial, avoidance, and behavioral and social disengagement

Seeking support and information—One method that survivors reported using to cope was by seeking social support from loved ones, medical teams, faith-based communities, and previous cancer survivors.

Other participants described how their support systems helped in coordinating care and logistics. For example, one participant described a friend who arranged a carpool system to her chemotherapy appointments, stating *she saved me from a lot of angst by doing what she did* (ID3). Some participants found value in support from those who have been through rectal cancer treatment before or those who also had an ostomy. One participant described how his support group helped him navigate his treatment and that he is now able to help others during their treatments as well, suggesting *I highly recommend anybody that goes through this, find a cancer support group* (ID7). Another described the importance of her church community during her treatment and recovery, *I don't believe I would have lived the first time if so many people in my church didn't pray for me* (ID13).

Finally, some participants reported trying to obtain information and knowledge after their rectal cancer diagnosis to be able to cope with the treatment and necessary decision making. Participants described utilizing online resources, seeking additional opinions, and consultation with their providers, causing one participant to worry about the *balance between seeming to be tagged as a worried patient, and also being a well-informed patient* (ID2). Whereas others attributed increased comfort levels due to providers adequately informing them of their treatment plans. Participants also described reassurance in knowing more information about their anatomy and gastrointestinal function as well as how others navigated survivorship.

Focus on attitudes and perspectives

Some rectal cancer survivors chose to reframe their attitude with optimism rather than dwelling on aspects they could not control, feeling *grateful* (ID2, ID11, ID14, ID5) and

lucky (ID4, ID6, ID15, ID11, ID8, ID17) to be *alive* (ID15, ID14, ID5). One participant explained *you've got to keep a positive attitude and just move forward* (ID4) with one even indicating, *I love my bag. I mean, the alternative is being dead, and this is much better* (ID14). This contrasts with many others who continued to struggle with their ostomies even years out from surgery. Several patients used their cancer treatment as a reason to refocus their daily efforts, prioritizing things, such as more family time over working longer hours, which helped to facilitate feelings of gratitude: *After I went through all the treatments and everything, I enjoy every day of my life right now... Even when days are bad, I appreciate it* (ID5).

Other rectal cancer survivors were able to cope with their diagnosis and treatment by comparing their situation to the worse-case scenarios and others whom they perceived as having worse circumstances. One patient explained he was *thankful* as he described his gastrointestinal issues of clustering *as minor issues compared to dying or having an ileostomy bag or colostomy bag (sic) for the rest of my life* (ID15). Another participant stated her chemotherapy treatment *wasn't as bad* because she *didn't lose [her] hair* and she could *kind of hide that [she was] sick* (ID10). Similarly, other patients reported not having visible signs of fighting cancer and therefore less struggles with body image.

Participants also reported feeling fortunate to have avoided postoperative complications or permanent ileostomies. Others reported comparing their experiences to those they heard about in support groups and feeling relieved their journey was not as difficult. Other participants described utilizing humor to cope with their diagnosis and treatment as well as connect with others. As one participant stated, *if you have humor, you can get through most things* (ID8).

Distancing strategies

Participants described engaging in several distancing strategies to navigate their illness experience, including escaping one's circumstances by distraction, denial, avoidance, and behavioral and social disengagement. Some rectal cancer survivors admitted that they *try not to think about* their diagnosis, treatment, and recovery as it is *overwhelming what you've been through* (ID3). One participant described going through his chemotherapy and radiation treatments *in a state of denial* and further described his outlook: *I just think going through it and not thinking about it and just living, you know, day-to-day is a better state of mind than dwelling and worrying about it because that just does not help* (ID10).

Other rectal cancer survivors reported coping with their diagnosis and treatment by avoiding their feelings regarding the topic, as one survivor explained, *sometimes I keep things bottled up inside me, and I don't let it out either* (ID8).

Other patients were able to cope with continued surveillance required by not being personally responsible for their follow-up plans. For example, one patient had an arrangement with his daughter so he could avoid the anxiety surrounding his colonoscopies.

She doesn't tell me until [2 to 3] day[s] before so I don't have the anxiety. I give myself those 2 days before the treatment, to have that anxiety. But other than that, I

refuse to have any other, because if you want to live, if you live your life like that, you're just miserable every day (ID5).

Some participants reported staying mentally or physically active. One survivor explained, *You can't sit around and mope, you know. I need to be active. My mind, you know, I need to have my hands involved in something (ID12).*

Another participant described her garden as a *therapeutic endeavor, stating in the very worst times I had, I can always go out and spend at least a half hour out there (ID7).*

Some survivors reported intentional separation from their social networks when diagnosed with cancer as they believed they either did not need the social support, or they did not want to bother anyone with their problems. One participant described his attitude: *I don't like to put anything on anybody. So, I really didn't tell anybody about my situation. Who needs to hear about that having stage III cancer? (ID11).*

Overall, many patients reported a range of emotional responses and multiple methods to cope with their rectal cancer journey.

Discussion

Our photo-elicitation study is the first of its kind to explore the emotional experiences and coping strategies of patients with rectal cancer. To better understand the psychological impacts and subsequent coping practices among rectal cancer survivors, we used a novel qualitative technique, which has uncovered the challenges experienced among those in this vulnerable and growing population. Rectal cancer survivors in our study reported experiencing emotional distress, including feelings of sadness and anxiety as well as fear of cancer recurrence despite no clinical signs of disease recurrence. To cope with their rectal cancer journey, survivors described utilizing methods to seek additional support and information, focusing on their attitudes and perspectives, and distancing themselves from their cancer diagnosis.

Although surveillance for recurrence is standardized for most cancer types, evaluation of the psychosocial needs after cancer therapy is less consistent, with many providers not addressing psychological health concerns at all in follow-up care. Despite generalized National Comprehensive Cancer Network Survivorship Guidelines to evaluate cancer survivors for anxiety, depression, trauma, and distress, as many as half of United States cancer survivors overall report that their physicians never discuss their social and emotional needs after cancer therapy.²⁸ In a study eliciting patient and surgeon perspectives on colorectal cancer survivor needs, 26% of patients reported addressing their emotional state as a top 3 priority in follow-up care while no surgeons recognized this as a key issue for survivors.²⁹ Moreover, at some point during their treatment and recovery, more than one-third of patients with cancer will experience clinically significant psychological distress, which has been shown to reduce quality of life and negatively impact self-care tasks and treatment adherence.^{30,31} Together, these data and our study findings emphasize the need for providers to recognize distress among cancer survivors regardless of duration from diagnosis. One potential intervention may be the use of the Distress Thermometer, which

has been validated in patients with colorectal cancer.³² Studies demonstrate that the distress thermometer is a simple and effective screening tool for presence and severity of distress in a variety of ambulatory patients with cancer.³³

As evidenced in our study and throughout existing literature, despite curative intent treatment, many patients with cancer experience a persistent fear of cancer recurrence, which has been associated with increased levels of anxiety, depression, intrusive thoughts, post-traumatic stress disorder, and reduced social and emotional quality of life.^{34–38} However, this fear of recurrence tends to be incongruent with a patient's actual risk of recurrence based on historical and patient-specific data.³⁹ Along with multidisciplinary tumor boards, surgeons and other providers should be more explicit about the success or failure of a patient's treatment and educate patients on their individualized risk of cancer recurrence to reduce excessive fear.⁴⁰

Rectal cancer survivors have prolonged psychological health concerns and require continued support. In breast cancer survivors, formal, multidisciplinary survivorship clinics have been shown to improve levels of depression, anxiety, and overall distress by recognizing and addressing ongoing physical and psychological symptoms.⁴¹ We believe a similar model, encompassing cancer surveillance, physical symptom management, and psychological support services, would be beneficial in rectal cancer survivors as well. Ideally, survivors would be able to seek care with mental health professionals experienced in the management of cancer-related psychological distress. However, due to logistical and financial constraints as well as patient geographics and preferences, we recognize that all rectal cancer patients may not have access to such clinics. Therefore, in addition to increasing screening and referral performed by a patient's cancer care providers, we believe primary care physicians should be empowered to screen for distress and identify appropriate resources for rectal cancer survivors when needed. Alternatively, virtual services from survivorship clinics may be offered to expand the amount of support available for rectal cancer survivors.

Our study has limitations. Most notably, although our study population is reflective of the rectal cancer population in Michigan with regard to sex and age, it is not representative of race and ethnicity, and therefore, may not be representative of overall rectal cancer survivors and their experiences.⁴² Additionally, our sample consists of those older than 50 years who may have distinctly different experiences than younger patients.³⁵ The majority of patients included in this study were also early stage, and it is possible that later stage patients might experience differing levels of psychological distress or greater gratitude that they survived even if they find managing ongoing symptoms to be challenging or inconvenient. Furthermore, most of our patients were of higher socioeconomic statuses, which may underestimate distress overall with studies demonstrating higher distress among those of lower socioeconomic status.⁴³ Finally, due to research restrictions imposed by COVID-19, we modified our research protocol by limiting participation to those with smartphone access and a working e-mail address. This may have further selected for patients of certain socioeconomic groups and might limit how broadly applicable the findings are for patients with rectal cancer. Despite this, our results represent the most in-depth exploration of rectal cancer survivor's emotional experiences and coping strategies and provide further evidence for enhanced rectal cancer survivorship care. Future work may focus on the psychological

experiences of an expanded population of patients with rectal cancer and an examination of specific coping strategies in decreasing psychological distress and improving the overall well-being among this group.

As therapy for rectal cancer continues to improve, providers must shift their focus to treating cancer as a short-term encounter to treating survivorship as a life-long state, which includes prioritizing the psychologic health of survivors. Although surgeons are not trained to provide psychosocial services specifically, they may serve as an appropriate screening system, refer to appropriate services when necessary, and educate patients on accurate risks of recurrence to minimize anxiety over surveillance and recurrence. Ultimately, rectal cancer survivors may benefit most from a multidisciplinary approach, which provides holistic, longitudinal care.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1.**Rectal Cancer Survivor Characteristics**

	N	%
Sex		
Male	9	45%
Female	11	55%
Age (range 38–80; mean 59.6)		
30–39	2	10%
40–49	1	5%
50–59	6	30%
60–69	7	35%
70–79	3	15%
80+	1	5%
Race		
White	19	95%
Asian	1	5%
Type of Surgery		
Low Anterior Resection	16	80%
Abdominoperineal Resection	4	20%
Pathology		
Stage 0	11	55%
Stage 1	5	25%
Stage 2	2	10%
Stage 3	1	5%
Missing	1	5%
Years Post-Op		
2–3	5	25%
3–4	7	35%
4–5	4	20%
> 5	4	20%

Table 2.

Exemplary Quotes Displaying in Rectal Cancer Survivor's Emotional Responses

Emotions	Exemplary Quotes
Sadness	<p><i>"Only when [my ostomy] acts up, then I get really, I get really down. I mean, it's not like it does it all the time, but when it does, it really acts up. I mean, it's to where I have to change. It leaks, and I have to change, there's times when I have to change like three or four times within a 24-hour period. And that really will depress you."</i> (ID8)</p> <p><i>"At one point, I really didn't want to live anymore."</i> (ID5)</p>
Anxiety	<p><i>"Right now, the medication I'm on keeps everything under control, but I have already kind of like future anxiety about like, well, if this doesn't remain in control, only having one bathroom, like that's not going to work."</i> (ID10)</p> <p><i>"There's an anxiety that, you know, like when I know I'm going to travel, even a day trip, sometimes I start getting a little worried."</i> (ID6)</p> <p><i>"I don't have any control over it. It's really distressing."</i> (ID2 - discussing amount of waste she produces from her ostomy)</p>
Fear	<p><i>"I mean, I'm always, in the back of my brain I go, what happens if it comes back, you know, kind of deal?"</i> (ID11)</p> <p><i>"You're scared, so you don't want to eat anything that you're not supposed to. So it's kind of like you just give up the food."</i> (ID18)</p>

Table 3.

Exemplary Quotes Displaying Coping Strategies Employed by Rectal Cancer Survivors

Coping Strategies	Exemplary Quote
Seeking Support and Information	<p><i>“They were actually up here for most of the time when I had the surgeries, I think. Yeah, so, I mean, they were a big help, obviously. They were just kind of always around. My mom stayed with me for, I mean, probably a couple weeks, actually.”</i>(ID16)</p> <p><i>“I got to be grateful to God.”</i> (ID11)</p> <p><i>“You can go online, and there are sites for people talking about ostomy . . . who knew you could go online and see hints for ostomy care? I just happened to google ostomy care. And up came, there are people who blog about it. What? Who knew? It would be interesting to know what to do. There are so many things to find out, aren't there?”</i>(ID14)</p>
Focus on Attitudes and Perspectives	<p><i>“Oh, you think you're deprived, I think. Sometimes you go, geez, you know, but I just stop and think of how fortunate I am, which usually kind of brings me out of that funk, you know. Well, I don't have an ostomy bag. I don't have Crohn's disease. . . And when I spoke with [doctor] before, when all this started, she said, you know, you need to be aware that you could have clustering. You could be in the bathroom several times a day. And I went, you know, how many times a day? And she said, I have a patient that's in there as many times as 31 times a day. You know, and all that was a factor in why I think like I do, because I don't, I'm very fortunate compared to a lot of people who have these problems.”</i> (ID6)</p> <p><i>“We just laugh about it. That's all I can do.”</i> (ID3)</p>
Distancing Strategies	<p><i>“Well, I don't know. You get, like you feel like people don't really want to hear your problems.”</i> (ID18)</p> <p><i>“It's hard sometimes when I think about it to consider myself a cancer survivor because I just feel like, I feel like I never had cancer, you know what I mean? And I did, obviously, or else I wouldn't, we wouldn't be having this conversation. But it, I, mine was so, I, it was caught so early and removed, and I haven't had a huge amount of side effects to even have to deal with, right, that I don't, I almost find it to be like disingenuous to consider myself a cancer survivor because you see people that are cancer survivors, and they're, you know, they have lots of issues, right, whereas me, I don't, I pretty much have gone about normal life at this point.”</i> (ID17)</p>