








ORIGINAL ARTICLE

Psychological and sexual distress in rectal cancer patients and partners

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Abstract

Background: Rectal cancer (RC) patients experience unique sources of distress, including sexual dysfunction and body image concerns, which can also cause distress among partners. This preliminary study investigated patterns of psychological distress, sexual functioning, sexual distress, and relationship satisfaction among RC patient-partner couples at pivotal points during cancer treatment.

Methods: Twenty couples participated ($N = 40$). Patients and partners completed a series of validated measures of psychological distress (ET), sexual functioning (FSFI; IIEF), sexual distress (GMSEX; Sexual Distress Scale) and relationship satisfaction (GMREL) at time of diagnosis, 3 weeks after radiation, 4 weeks post-surgery, and after chemotherapy and surgery for ostomy closure. Descriptive statistics, t -tests, and repeated-measures ANOVA were used to analyze scores over time, first for patients and partners, and then by sex.

Results: Relationship satisfaction remained elevated over time. In this sample, 55% of patients and 78.9% of partners reported clinically significant rates of psychological distress at diagnosis, which decreased to 23% and 46% respectively at the last assessment. Sexual satisfaction and distress worsened for patients and partners between baseline and surgery for ostomy closure. Both male and female participants reported statistically significant declines in sexual function from baseline to end of treatment ($p < 0.05$).

Discussion: Relative to relationship satisfaction, psychological and sexual health outcomes seem more vulnerable to the effects of RC treatment during the first year after diagnosis, both for patients and partners and for men and women. Results support the need for psychosocial care and sexual education/counseling for couples coping with RC.

KEYWORDS

couples, dyadic research, psychological distress, rectal cancer, relationship satisfaction, sexual functioning

1 | INTRODUCTION

Rectal cancer (RC) is diagnosed in more than 43,000 Americans each year and carries a high risk of morbidity and mortality.¹ Beyond the oncologic risk of RC, the disease and its treatments --which include a combination of pelvic radiation therapy, chemotherapy, and surgery, often with a temporary or permanent ostomy-- have profound effects on quality of life.²⁻⁴ For instance, gastrointestinal and psychosocial symptoms negatively impact social and sexual functioning as well as financial status across the cancer care continuum.^{2,3,5,6}

While psychological distress is prevalent in oncology,⁷ RC patients have been shown to suffer greatly from it and to experience sources of distress that are unique to this population, including negative body image, bowel control/incontinence, and sexual dysfunction.^{4,8,9} Recent studies document an often pervasive effect of RC on patients' quality of life and sexual functioning. Compared to patients with colon cancer, those diagnosed with RC may be at risk for more frequent sexual problems.¹⁰ Similarly, Sun et al.² reported that RC survivors with permanent ostomy experienced lower health-related quality of life and greater dissatisfaction with appearance. Reese and colleagues found that body image distress and sexual quality of life impairments were common among RC patients, and were associated with worse psychosocial outcomes.⁴

Since RC patients face these physical, sexual, and body image problems, effects on their relationship with an intimate partner can be considerable.⁶ While it is well established that cancer distress affects both patients and their spouses/partners, as a result of the interdependence that exists within couples,¹¹⁻¹⁴ few studies have investigated health-related quality of life, marital functioning, and sexual health in the context of RC patients' close relationships,^{4,15,16} leaving an important gap in the literature. A recent systematic review of dyadic studies indicated that relationship factors can affect adjustment to colorectal cancer, as evidenced by lower depressive symptoms and emotional distress reported by couples characterized by disclosure and active engagement. In addition, significant correlations between patient and partner's measures, including the association between sexual and marital satisfaction, illustrate that cancer-related distress affects the quality of the relationship.¹⁷ However, studies included in this systematic review had several limitations: articles did not include patients with only RC, data were not analyzed separately for the colon and RC subgroups, and female patients were under-represented. A second aspect to consider when including both partners is that recruitment and retention of dyads for psychosocial research is deeply challenging,¹⁸⁻²⁰ as accessibility, competing priorities, and illness severity are barriers for study uptake. Although there is growing consensus that cancer is an interpersonal stressor, data from the literature indicate that couple response rate varies substantially, between 25% and 90%,¹⁸ and that careful consideration should be given to recruitment strategies able to support investigators' recruitment goals.^{18,19}

In this context, we conducted a preliminary study aimed at investigating psychological distress, sexual functioning, sexual

distress, and relationship satisfaction among RC patient-partners couples at pivotal points during cancer treatment. We examined changes over time on these factors for patients and their partners and any differences between the two individuals. The ultimate objective of the present contribution was to glean findings that could be of use to healthcare professionals in understanding the psychological sequelae of RC on the well-being of patients and partners, and to inform future development of interventions able to alleviate the distress experienced by couples.

2 | METHODS

2.1 | Research setting and patient population

This study was conducted at two academic cancer centers in the U.S. from August 2014 to December 2017. Potential participants were recruited by physicians and research study coordinators during outpatient visits after a new diagnosis of RC. Inclusion criteria were: (1) being an adult (18 years of age and older) with a histologically proven diagnosis of RC; (2) being in a significant partnered relationship or married, (3) receiving treatment (chemotherapy, radiation, surgery, or a combination of these treatments) at one of the study sites; and (4) being able to speak/read in English. Because the study design focused on couples, patients were excluded if the partner was not identified or was not willing to participate. The study was approved by the Institutional Review Board (IRB) of each cancer center. Informed consent forms were signed by each participant. Although same-sex couples were eligible, none were identified by the recruitment coordinators.

2.2 | Procedure

A convenience sample of patients and partners completed paper-and-pencil surveys either in the clinic or at home at four time points: "Time 1" (baseline), near the time of diagnosis and before initiating treatment; "Time 2," approximately 3 weeks after completing radiation; "Time 3," approximately 4 weeks post-surgery; and "Time 4," after chemotherapy and surgery for ostomy closure. The couples were instructed to complete the questionnaires independently.

2.3 | Instruments

The survey questionnaire was a combination of several validated instruments and additional sections designed by the research team specifically for the study. Sociodemographic characteristics such as age, sex, race/ethnicity, education, and employment status/type were collected at baseline for patients and partners. Clinical characteristics, including disease status, stage, treatment, surgery type and symptoms were self-reported, with missing data filled in by clinical query or through the patient's medical record.

Psychological distress was measured at each data collection point with the Emotion Thermometers,²¹ a self-report visual analog tool assessing five domains (distress, anxiety, depression, anger, and need for help) on a scale ranging from 0 to 10. The instrument has been shown to have excellent reliability (Cronbach's alpha 0.90), sensitivity (82.4%) and specificity (68.6%).^{21,22}

Sexual distress. The General Measure of Sexual Satisfaction (GMSEX) was used to examine sexual satisfaction at T1 (baseline) and T4 (after chemotherapy and ostomy closure). This 5-item scale contains five 7-point semantic differentials: "good-bad", "pleasant-unpleasant", "positive-negative", "satisfying-unsatisfying", and "valuable-worthless" in response to the request to assess the sexual relationship with the partner. Scores range from 5 to 35, with higher scores being indicative of greater sexual satisfaction. The instrument has demonstrated strong reliability and validity²³ in men and women (Cronbach's alpha 0.94 for both). In addition, the investigators utilized four items assessing how patients and partners were distressed by current sexual functioning, treatments' side effects, and sexual life in general to assess self-reported sexual distress at each assessment. Answers were recorded on a 5-point Likert scale ranging from zero (Not all distressed) to five (Extremely distressed) for a max score of 20, with higher scores indicating greater distress.

Sexual functioning was assessed with the Female Sexual Function Index (FSFI) and International Index of Erectile Function (IIEF) questionnaires at time of diagnosis (T1) and after surgery for ostomy closure (T4). The FSFI consists of 19 items rated on a 5-point response option measuring six domains: desire, subjective arousal, lubrication, orgasm, satisfaction, and pain. Higher scores are indicative of better functioning. The scale has demonstrated high internal consistency (Cronbach's alpha >0.82), test-retest reliability, and construct validity.²⁴ The IIEF includes 15 items assessing five domains: erectile function, orgasmic function, sexual desire, intercourse satisfaction, and overall satisfaction. Items are rated using a 5-point scale with higher numbers indicative of more positive functioning. The scale measures functioning over the previous 4 weeks and has demonstrated high internal consistency (Cronbach's alpha, range = 0.73–0.99) and test-retest reliability.^{25,26}

Relationship satisfaction: The General Measure of Relationship Satisfaction (GMREL)²⁷ contains five 7-point semantic differentials about the relationship with the partner and it was administered to both patients and partners at each data collection point. Higher scores indicate greater relationship satisfaction, with a maximum score of 35. The scale has shown strong reliability and validity^{23,27} in men (Cronbach's alpha 0.96) and women (Cronbach's alpha 0.96).²⁷

2.4 | Statistical analysis

Descriptive statistics were used to summarize scores over time for the entire cohort. Comparisons between patients and partners on emotional, relational, and sexual distress measures were conducted using paired samples *t*-tests for continuous variables. Individual

change across the multiple data collection points was assessed with repeated measures ANOVA, while repeated measures *t*-test was implemented to investigate changes between Time 1 and Time 4. Variables of interest were stratified by role and by sex to illustrate patterns of distress over time. SPSS (Version 26) was used for data management and analysis.

3 | RESULTS

3.1 | Sample characteristics

Twenty couples enrolled and completed baseline surveys (T1). Three couples separated during the study, leaving data from 12 couples at Time 2, 16 couples at Time 3, and 13 couples at Time 4. Additionally, for patients whose treatment plans did not include chemotherapy or radiation, Time 2 surveys were not administered. Baseline demographic and clinical characteristics are summarized in Table 1. Most couples were married (80%) and in long-term relationships ($M = 21.47$ years, $SD = 15.7$, Range 2–52). Rectal cancer patients had a mean age of 53.2 years, while partners were on average 51.6 years old. Overall, patients were males (60%), Non-Hispanic White, and highly educated. Approximately 60% were diagnosed with Stage III RC and 75% had received multiple types of treatments (surgery, radiotherapy, and chemotherapy). The most common surgery was low anterior resection with ostomy (66.7%).

3.2 | Psychological distress

Mean and variance indicators of the variables of interest (psychological distress, sexual distress, sexual functioning, and relationship satisfaction) are presented in Table S1 in Supporting Information. At Time 1, mean scores for both patients and partners were above the clinical cut-off score of four (the NCCN guideline's cut-off score prompting referral), indicating clinically meaningful psychological distress. While no significant changes in psychological distress were detected over time for partners, patients' distress significantly decreased between T1 and T4 ($t_{(12)} = 2.95$, $p < 0.05$). Partners' distress was elevated at time of diagnosis and it decreased at T2, remaining overall stable at the last two assessments (Figure 1). In addition to distress, patients' anxiety decreased over time ($F_{(3,21)} = 3.68$, $p < 0.05$). Given the growing attention to psychological distress detection and management in cancer care, the prevalence of clinical distress as defined by the standard cut-off of ≥ 4 on the selected instrument was also examined for both patients and partners. At T1, 55% of patients and 79% of partners reported distress in the clinical range which requires a response from a psychosocial provider. These percentages decreased at T2, where 25% of patients and 31% of partners were clinically distressed, only to increase again after surgery (T3) where half of patients and partners met the clinical criterion. At T4, however, 23% of patients and 46% of partners were reporting psychological distress above the cut-off.

TABLE 1 Sample characteristics at baseline (N = 20 dyads)

Sociodemographic Variables	Patients (n = 20)	Partners (n = 20)
Age (mean)	53.20 (SD = 11.31; Range 37–74)	51.55 (SD = 11.01; Range 33–72)
Sex		
Males	60.0% (12)	40.0% (8)
Females	40.0% (8)	60.0% (12)
Race		
White/Caucasian	95.0% (19)	90.0% (18)
African American	-	-
Hispanic/Latino	-	-
Arab or Arab-American	5.0% (1)	-
American Indian or Alaska Native	-	5.0% (1)
Asian or Pacific Islander	-	5.0% (1)
Other	-	-
Education		
Grade school or less	5.0% (1)	-
Some high school	-	-
High school/GED	15.0% (3)	21.1% (4)
Some college/Technical school	40.0% (8)	31.6% (6)
Bachelor's degree	25.0% (5)	21.1% (4)
Graduate degree	15.0% (3)	26.3% (5)
Employment status		
Employed	55.0% (11)	55.0% (11)
Not employed	45.0% (9)	45.0% (9)
Job type		
Not skilled labor	18.2% (2)	18.0% (2)
Skilled labor	9.1% (1)	-
Professional	54.5% (6)	63.6% (7)
Managerial	18.2% (2)	18.2% (2)
Clinical variables		
Clinical stage		
Stage I	15.0% (3)	
Stage II	20.0% (4)	
Stage III	60.0% (12)	
Stage IV	5.0% (1)	
Treatment type		
Surgery + Radiotherapy + Chemotherapy	75.0% (15)	
Radiotherapy + hemotherapy	5.0% (1)	
Surgery + Chemotherapy	10.0% (2)	
Surgery	10.0% (2)	

Note: Not all groups of n values and % add up to the reported sample size because of missing data.

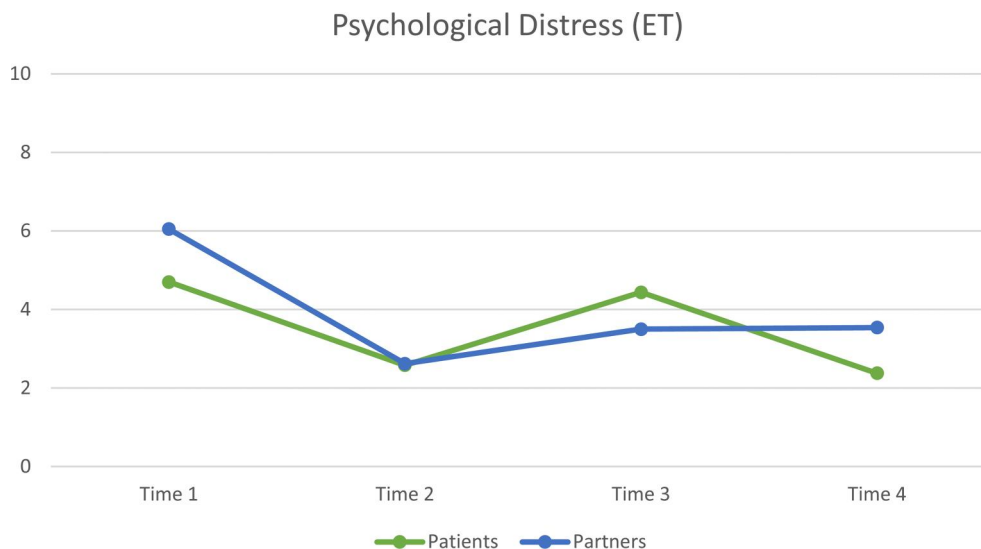


FIGURE 1 Patients and partners' mean scores for psychological distress over time

3.3 | Sexual distress

Sexual distress increased for both patients and partners from baseline (T1) to T3, the data collection point where the highest scores for distress concerning the individual's sex life were reported (Figure 2). For patients, the increase in sexual distress scores over time was statistically significant ($F_{(3,18)} = 4.62, p < 0.05$). As sexual distress increased, sexual satisfaction (GMSEX; Figure 3) decreased for both patients and partners, with a statistically significant reduction between baseline (T1) and the end of treatment (T4) among partners ($t_{(9)} = 3.47, p < 0.01$).

3.4 | Sexual functioning

Sexual function of both patients and partners was impaired, as evidenced by the reported decline in orgasmic function, sexual desire, arousal, and satisfaction between T1 and T4; with the only exception recorded for male partners (Table 15). The small sample size at the last assessment affects the ability to investigate differences by both sex and role together. For this reason, repeated measures *t*-tests were used to detect differences for male and female participants separately. Sexual function worsened significantly for female participants, as evidenced by reduced FSFI total score ($t_{(12)} = 2.30, p < 0.05$), satisfaction ($t_{(12)} = 2.68, p < 0.05$) and pain ($t_{(12)} = 3.16, p < 0.01$). Among male respondents, erectile function significantly declined ($t_{(11)} = 2.89, p < 0.05$). To determine the clinical significance of the sexual problems reported by women, the cut-off score of less than 26.55 on the overall scale²⁸ was used. For men the cut-off score of 25 was used for assessing erectile dysfunction.²⁹ At T1, 57.1% of women presented clinically significant sexual problems; this percentage increased to 84.6% at end of treatment. Among male respondents, 45% reported erectile dysfunction at the beginning of

the study, whereas 66.7% met the criteria at T4. The small sample size at the last data collection, however, recommends interpreting this result with caution.

3.5 | Relationship satisfaction

Relationship satisfaction scores were high before treatment initiation and remained elevated across all measurements for patients and partners, with no significant differences between patients and partners observed across the four data collection points.

4 | DISCUSSION

This preliminary study investigated patterns of psychological distress, sexual functioning, sexual distress, and relationship satisfaction among couples facing RC at pivotal time points following diagnosis and initial treatment. Our findings revealed that a significant proportion of patients and partners presented psychological and sexual distress during the first year after diagnosis, with different patterns occurring over time. For instance, whereas relationship satisfaction remained elevated, sexual health measures tended to show declines during the first-year post-diagnosis. Furthermore, the study suggests that the distress of patients and partners is not static, but rather that couples may be more vulnerable to the effects of treatments on their psychological well-being and sexual health outcomes at certain times of the cancer care continuum: at diagnosis, when psychological distress was elevated for both, and after surgery, when sexual distress peaked and approximately 50% of patients and partners scored above the threshold for psychological distress. Sexual functioning worsened for both male and female participants, as indicated by the elevated rate of clinically significant sexual problems at the last assessment.

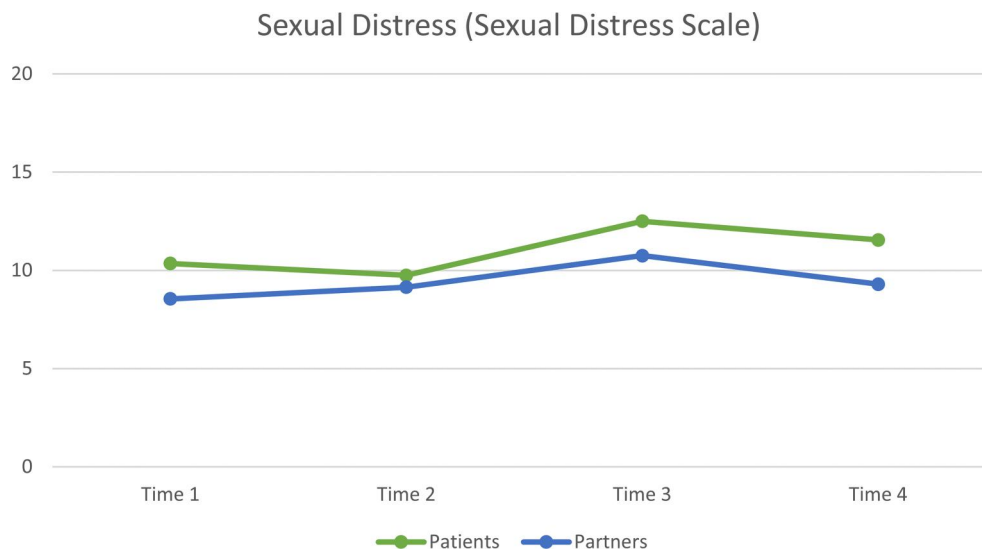


FIGURE 2 Patients and partners' mean scores for sexual distress over time

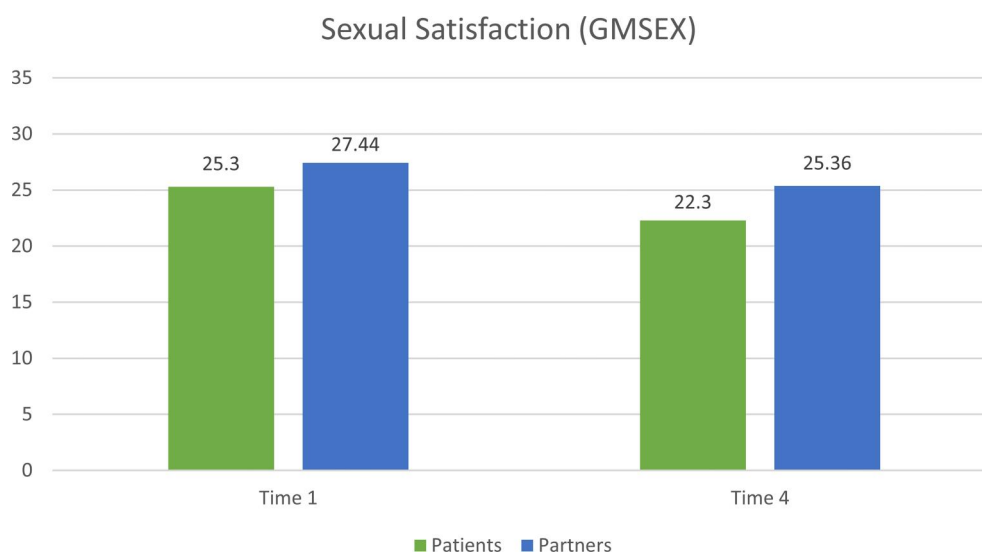


FIGURE 3 Patients and partners' mean scores for sexual satisfaction at diagnosis (T1) and end of treatment (T4)

Similar rates of sexual dysfunction were reported by earlier studies investigating RC and patients' quality of life. For example, a longitudinal prospective survey concluded that significant sexual dysfunction extended from the start of treatment up to 1 year after surgery, with worse sexual enjoyment for female patients.³⁰ Reese and colleagues analyzed sexual distress, body image, and psychosocial outcomes at two data collection points: while body image improved at the 6-month assessment, sexual dysfunction remained stable and characterized approximately 58% of the sample.⁴ Results from the present work provide further support for the persistence of sexual impairment for patients, while also presenting unique data regarding sexual outcomes of partners. In our sample, partners' sexual distress was mostly elevated at time of surgery, while affected sexual satisfaction and functioning persisted at the last measurement. Findings from a qualitative study by Abelson et al.⁹ and a

thematic analysis by Sun et al.² help clarify this result: as post-operative sources of distress include dealing with the symptoms, complications from surgery, and the experience of recovery, it is possible that worse outcomes occur when significant losses in sexual function become evident.^{2,6,9}

While other contributions have frequently examined the psychosocial experience of the patient, our investigation focused on adjusting to RC through the lens of the couple's relationship. Although relationship satisfaction remained stable over time, a finding previously documented by Traa and colleagues,¹⁶ patients and partners' psychological distress scores were elevated at diagnosis and increased again after surgery. Prevalence of distress was elevated at the first data collection point, when 55% of patients and 79% of partners reported clinically significant rates of distress, decreased during radiation, only to increase again after surgery and

remained elevated for partners at the end of treatment. These results are consistent with the extant literature addressing cancer as a relational illness, where patients and partners both experience distress and mutually contribute to cope with the disease.^{11,13,17,31} Differences between the two members of the dyad were noted at the last assessment, suggesting that their experiences may diverge after active treatment. As partners' caregiving role may continue and treatment-related sexual problems persist, they may be facing unalterable intimate and sexual changes that affect quality of life and couple functioning.^{2,9,14,31-33} In previous studies on colorectal cancer, positive relationship processes contributed to better outcomes and significant correlations existed between patients and partners' distress,¹⁷ suggesting that greater consideration should be given to caregivers⁶ and to systematically screen and attend to the psychosocial needs of both partners.

Challenges with recruitment and retention of couples characterized the present work, confirming the complexities associated with couple-based research in psychosocial oncology.¹⁸ Barriers to effective recruitment included both partners' interest in the study, time availability, limited advertisement, and modality for survey completion. We also recognize the distinct challenges RC patients experience in terms of distress, body image, sexual dysfunction, and quality of life, which may have also acted as barriers for study enrollment.²⁻⁶ Empirically based strategies such as multiple recruitment approaches, moving timing and setting of recruitment to follow-up appointments, reducing participant burden through tailored data collection strategies, and the clear communication of benefits for participants and the larger community of survivors and caregivers may address these challenges.¹⁸⁻²⁰

4.1 | Limitations

Several limitations affect the present work and warrant discussion. First, the small sample size and lack of diversity in socio-demographic characteristics limited the generalizability of findings beyond the setting of a preliminary study, especially as cancer survivors represent a heterogeneous group of experiences and needs. Additionally, the modest number of couples with fully completed surveys across the data collection points prevented the investigators from conducting more complex analyses of the variables impacting patterns of distress over time or the relationship between these measures. Future quantitative and qualitative studies are therefore recommended to further characterize the association between psychological distress, relationship functioning, and sexual health measures between partners, while also investigating antecedents of individual and relational well-being such as coping flexibility and dyadic coping behaviors. Similarly, dyadic data analysis approaches accounting for the non-independence of partners' scores couldn't be applied. Although aggregated data appear to indicate that members of each couple experienced similar levels of distress and satisfaction, we observed that a few had discrepant scores, suggesting that future research should explore within-dyads congruence and whether

non-concordant couples are at higher risk for worse outcomes. Finally, while the selection of four pivotal data collection points contributes to illustrate changes in psychosocial, sexual, and relational well-being, a longer timeline inclusive of follow-up visits after recovery for ileostomy closure would be informative.

4.2 | Clinical implications

This study adds to a scant evidence base of dyadic studies focused on RC and begins to offer greater understanding of the psychological experience of both partners. While elevated relationship functioning indicates that couples in long-term relationships may be able to withstand the effects of the illness during the first-year post-diagnosis, sexual health outcomes and patterns of distress reported by patients and partners after active treatment should be investigated further. Moreover, while psychological distress may improve over time, no such improvement was detected among measures that targeted sexual distress and function, especially for patients and female caregivers. Thus, the present work emphasizes the need to offer interventions to address sexual problems, especially at the beginning stages of treatment. Couples may benefit from psychoeducational or intimacy-enhancing programs^{10,34,35} that equip them with the resources to cope with the long-term consequences of surgery on their well-being and sexual health.

In contrast with the prevailing need for screening and intervention related to sexual problems in oncology care, as evidenced by the inclusion of sexual health among the NCCN Clinical Practice Guidelines³⁶ and ASCO adaptation of the Cancer Care Ontario Guideline,³⁷ RC patients still receive inadequate information and support,^{9,38} reluctance to disclose sexual health difficulties persists, and limited access to services has been documented.³⁹ Therefore, healthcare providers should introduce the topic of sexual health early to build rapport with the couple and to facilitate the communication about treatment-related side effects and functional consequences when the need will arise.⁴⁰ We recommend implementing a multidisciplinary approach where a sexual health consultation can be routinely offered following diagnosis and before treatment commencement. A licensed professional trained in sexual health can be present to discuss the impact of RC on this domain and offer sex therapy or counseling at times of greater vulnerability. Additionally, connection to resources can be facilitated by healthcare providers routinely offering referrals to psychosocial services, attending educational events/workshops, or familiarizing with different professionals' functions (sexuality educators, counselors, and therapists).

5 | CONCLUSIONS

While psychological distress and sexual dysfunction are of two of the most prevalent and persistent side effects of RC, little is known about how couples cope with them over time and how to provide

psychosocial care that is responsive to their unique needs across the care continuum.^{17,31,39} Logical next steps include replication of this longitudinal survey with larger samples and qualitative studies inclusive of patients, partners, and providers to understand how to address couples' distress and functional impairments within the context of the current healthcare environment.

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CONFLICT OF INTEREST

The authors have no relevant financial or non-financial interests to disclose.

AUTHOR CONTRIBUTIONS

Chiara Acquati: conceptualization, methodology, formal analysis, writing and editing. Samantha Hendren: conceptualization, methodology, formal analysis, writing and editing. Daniela Wittmann: conceptualization, methodology, formal analysis, writing and editing. Jennifer Barsky Reese: conceptualization, methodology, writing and editing. Eli Karam: conceptualization, methodology, writing and editing. Ashley Duby: conceptualization, methodology, writing and editing. Kelli Bullard Dunn: conceptualization, methodology, writing and editing. Karen Kayser: conceptualization, methodology, formal analysis, writing and editing.

ETHICS APPROVAL

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. The study was approved by the IRB of the University of Louisville (14.0344) and University of Michigan (HUM00088080).

CONSENT TO PARTICIPATE

Informed consent was obtained from all individual participants included in the study.

CONSENT FOR PUBLICATION

All authors have approved the current version of the manuscript for publication.

DATA AVAILABILITY STATEMENT

Data and study materials are available upon request.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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