

# Predictors of Long-Term Quality of Life for Survivors of Stage II/III Rectal Cancer in the Cancer Care Outcomes Research and Surveillance Consortium

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## Abstract

**Purpose:** Many patients do not receive guideline-recommended neoadjuvant chemoradiotherapy for resectable rectal cancer. Little is known regarding long-term quality of life (QOL) associated with various treatment approaches. Our objective was to determine patient characteristics and subsequent QOL associated with treatment approach.

**Methods:** Our study was a geographically diverse population- and health system–based cohort study that included adults age 21 years or older with newly diagnosed stage II/III rectal cancer who were recruited from 2003 to 2005. Eligible patients were contacted 1 to 4 months after diagnosis and asked to participate in a telephone survey and to consent to medical record review, with separate follow-up QOL surveys conducted 1 and 7 years after diagnosis.

**Results:** Two hundred thirty-nine patients with stage II/III rectal cancer were included in this analysis. Younger age

(< 65 v  $\geq$  65 years: odds ratio, 2.49; 95% CI, 1.33 to 4.65) was significantly associated with increased odds of receiving neoadjuvant or adjuvant chemoradiotherapy. The adjuvant chemoradiotherapy group had significantly worse mean Euro-Qol-5D (range, 0 to 1) and Short Form-12 physical health component scores (standardized mean, 50) at 1-year follow-up than the neoadjuvant chemoradiotherapy group (0.75 v 0.85;  $P = .002$ ; 37.2 v 43.3;  $P = .01$ , respectively) and the group that received only one or neither form of treatment (0.75 v 0.85;  $P = .02$ ; 37.2 v 45.1;  $P = .008$ , respectively).

**Conclusion:** Neoadjuvant treatment may result in better QOL and functional status 1 year after diagnosis. Further evaluation of patient and provider reasons for not pursuing neoadjuvant therapy is necessary to determine how and where to target process improvement and/or education efforts to ensure that patients have access to recommended treatment options.

## Introduction

Since 1990, a multimodality approach of surgery and chemoradiotherapy has been the standard of care for stages II/III rectal cancer.<sup>1</sup> Subsequently, neoadjuvant chemoradiotherapy was shown to improve local control and reduce toxicity in the German Rectal Cancer Study Group trial that was published in 2004<sup>2</sup>; these results persisted after a median follow-up of 11 years.<sup>3</sup> Although neoadjuvant chemoradiotherapy is the National Comprehensive Cancer Network (NCCN) guideline–recommended treatment approach,<sup>4</sup> many patients do not receive neoadjuvant or even adjuvant chemoradiotherapy.

Analyses of SEER data demonstrate that the proportion of patients with stages II and III rectal cancer who do not receive any radiotherapy is slowly decreasing,<sup>5,6</sup> but approximately one quarter of patients diagnosed in 2010 still did not receive radiotherapy.<sup>7</sup> The reasons for non–guideline concordant care are unclear.<sup>5,6,8</sup> Studies that were based on SEER data for those with stages II and III rectal cancer found that patients who did not receive radiotherapy were older compared with those who did receive it.<sup>5,6,9,10</sup> Black patients are also less likely to receive radiotherapy compared with white patients.<sup>9-11</sup> Unfortunately, SEER data do not allow for examination of patient preferences, comorbidities, adverse therapy

effects, and other clinical factors that may elucidate possible explanations for nonreceipt of chemoradiotherapy.

Although neoadjuvant chemoradiotherapy has been demonstrated to decrease toxicity and local recurrence compared with adjuvant chemoradiotherapy, few studies have examined long-term differences in quality of life (QOL) between the two approaches.<sup>12,13</sup> Neoadjuvant or adjuvant chemoradiotherapy can increase the risk for long-term bowel/anorectal, urinary, and sexual dysfunction.<sup>13-24</sup> In this study, we address these gaps in our understanding by using data from CanCORS (the Cancer Care Outcomes Research and Surveillance Consortium). The two objectives of this study were to examine patient characteristics associated with the receipt and sequence of therapy, and to evaluate the impact of therapy receipt and sequence on long-term QOL and functional status among disease-free survivors.

## Methods

### Study Population and Design

CanCORS is a geographically diverse population- and health system–based cohort study that included 4,723 adults age 21 years or older with newly diagnosed, pathologically confirmed, invasive colorectal cancer who were recruited between 2003 and 2005. Patients were recruited from four geographically

based cancer registries in Northern California, Los Angeles County, North Carolina, and Alabama, from five large health maintenance organizations (HMOs) that are part of the Cancer Research Network, and from five Veterans Affairs (VA) hospitals.

As described previously,<sup>25</sup> eligible patients from these sites were contacted approximately 4 months after cancer diagnosis and asked to participate in a baseline telephone survey, with interview type (full, brief, surrogate interview for live patient, surrogate interview for deceased patient) dependent on patient status. Interviews included questions about sociodemographic characteristics, treatments, providers, goals/beliefs/preferences with regard to treatment options, symptoms, and quality of life.<sup>26</sup>

Medical records were abstracted from 3 months before diagnosis through at least 15 months after diagnosis. The CanCORS medical record abstraction (MRA) database contains information on tumor characteristics and the acute treatment phase, including provider types visited, staging procedures, and surgery, chemotherapy, and radiotherapy regimens.<sup>25-27</sup> Medical record information was also used to assign American Joint Committee on Cancer collaborative stage<sup>28</sup> and to determine Adult Comorbidity Evaluation–27<sup>29</sup> comorbidity indicators.

CanCORS participants were also surveyed approximately 1 and 7 years after diagnosis. Functional status was measured at baseline and in both follow-up surveys using the Short Form-12 (SF-12).<sup>30,31</sup> QOL was measured by the EuroQoL-5D (EQ-5D) scale.<sup>32-34</sup> Defecation problems such as frequency of bowel movements, unintentional release of stools, difficulty or pain with moving bowels, and blood with stools were assessed via a Defecation Scale developed by CanCORS investigators.<sup>26</sup> The lower the Defecation Scale score, the more problems reported by the participant (ie, higher scores correspond to better function).

Analyses included patients with stage II or III adenocarcinoma of the rectum with no previous history of cancer, except for nonmelanoma skin cancers. Stage was based on a hierarchy of best available evidence with Collaborative Stage (calculated American Joint Committee on Cancer stage based on medical record–abstracted tumor size, extension, lymph nodes, and metastases) at the top of the hierarchy. Pretreatment clinical stage was generally used for patients who received neoadjuvant therapy as opposed to pathologic staging at surgery. The algorithm for determining stage is described in detail elsewhere.<sup>35</sup> Those with tumors at the rectosigmoid junction were excluded, given that administration of chemotherapy and radiotherapy is not included in guidelines for higher lesions. The study was approved by human subjects committees at all participating institutions.

## Data Analysis

Patients were divided into two groups: first, those who received neoadjuvant chemoradiotherapy or adjuvant chemoradiotherapy; and second, those who received only chemotherapy or only radiotherapy (regardless of when administered) or neither.  $\chi^2$  and Fisher's exact tests were used to compare the groups on key

variables obtained from the CanCORS survey and MRA database. Multivariable logistic regression was used to examine patient characteristics associated with the two groups described; all variables listed in [Table 1](#) and [Appendix Table A1](#) (online only) were considered for inclusion in the models. Variables that were not significant predictors after adjustment for other covariates ( $P > .10$ ) were removed in a backward selection process.

For QOL analyses, the study population was limited to patients who were alive and disease-free at 7 years postdiagnosis. Group one was further stratified into patients who received neoadjuvant chemoradiotherapy (as a proxy measure for attempted guideline care) versus adjuvant chemoradiotherapy. Patients receiving both neoadjuvant chemoradiotherapy as well as adjuvant chemotherapy were placed in the neoadjuvant group. Multivariable linear regression was used to determine the relationship at baseline between the functional status/QOL scores mentioned previously and candidate predictor variables listed in [Table 1](#) and [Appendix Table A1](#). This set of candidate predictors, plus the baseline value of the outcome variable, was also used to model functional status/QOL measured in the 1- and 7-year follow-up surveys. Treatment was considered a key predictor and was not a candidate for removal in the backward selection procedure, as were baseline scores for the 1- and 7-year outcome measures. For all logistic regressions, patients were excluded if they were missing information for any variable included in that specific model. The minimum number of covariates in any of the models was one, and the maximum number was eight. All statistical analyses were performed in SAS software (version 9.3; SAS Institute, Cary, NC) on version 12 of the CanCORS surveys and MRA (version 17 core data set).

## Results

A total of 239 patients met the inclusion criteria for the objective 1 analysis. One hundred eighty-three patients (77%) received either neoadjuvant or adjuvant chemoradiotherapy, and 56 (23%) received only one treatment modality or neither ([Figure 1](#)). Among those who received chemoradiotherapy, 119 (65%) received neoadjuvant chemoradiotherapy and 64 (35%) received adjuvant chemoradiotherapy ([Figure 1](#)). [Figure 1](#) shows the number who received each therapy and the sequence in which therapy was received; more detailed information on those receiving neoadjuvant versus adjuvant chemotherapy and radiotherapy is described in the article by Charlton et al.<sup>8</sup>

## Patient Characteristics Associated With Receipt of Chemoradiotherapy

The characteristics of the two study groups are presented in [Table 1](#). Compared with the group that received only one or neither treatment modality, higher proportions of the group that received both (either neoadjuvantly or adjuvantly) were younger than age 75 years, had received recommended magnetic resonance imaging of the pelvis or transrectal ultrasound for locoregional staging, positron emission tomography and carcinoembryonic antigen testing during the staging/pretrat-

**Table 1.** Patient Demographic and Clinical Characteristics

Characteristic (N = 239)	Chemotherapy and Radiotherapy (n = 183; % [No.])	Not Both/Neither* (n = 56; % [No.])	P
Female sex	35 (64)	41 (23)	.41
Lives alone	61 (112)	64 (36)	.68
White race	62 (113)	61 (34)	.89
Age group, years			
< 55	32 (59)	20 (11)	< .01
55-64	32 (58)	25 (14)	
65-74	21 (38)	16 (9)	
≥ 75	15 (28)	39 (22)	
Insurance			
Covered by at least one insurer/payer	83 (151)	81 (44)	.72
None/NA/missing	17 (32)	19 (12)	
Education			
< 12 years	46 (85)	50 (28)	.64
≥ 13 years	54 (98)	50 (28)	
Source of case			
HMO	64 (117)	71 (40)	.18
Cancer registry	21 (39)	23 (13)	
VA	15 (27)	5 (3)	
Locoregional clinical staging			
MRI or TRUS	34 (63)	18 (10)	.02
PET	29 (53)	14 (8)	.03
CEA	86 (158)	73 (41)	.02
Stage III (v stage II)	54 (99)	59 (33)	.52
Tumor size, mm			
Median	48	47	.81
IQR	30-55	30-60	
Sphincter status			
Preserved	63 (115)	80 (45)	.01
Removed	37 (68)	20 (11)	
Chemotherapy (n = 203)			
Neoadjuvant	65 (119)	0 (0)	< .01
Adjuvant	35 (64)	100 (20)	
Radiotherapy (n = 188)			
Neoadjuvant	65 (119)	60 (3)	.82
Adjuvant	35 (64)	40 (2)	
Comorbidity			
None	34 (62)	25 (14)	.61
Mild	41 (75)	48 (27)	
Moderate	17 (31)	20 (11)	
Severe	8 (15)	7 (4)	
Baseline survey type			
Full	76 (139)	63 (35)	.03
Brief	14 (25)	16 (9)	
Surrogate, live	9 (17)	14 (8)	
Surrogate, deceased	1 (2)	7 (4)	
State of health rating			
Baseline			
Mean	68	71	.40
SD	22	22	

*continued on next page*

**Table 1.** (continued)

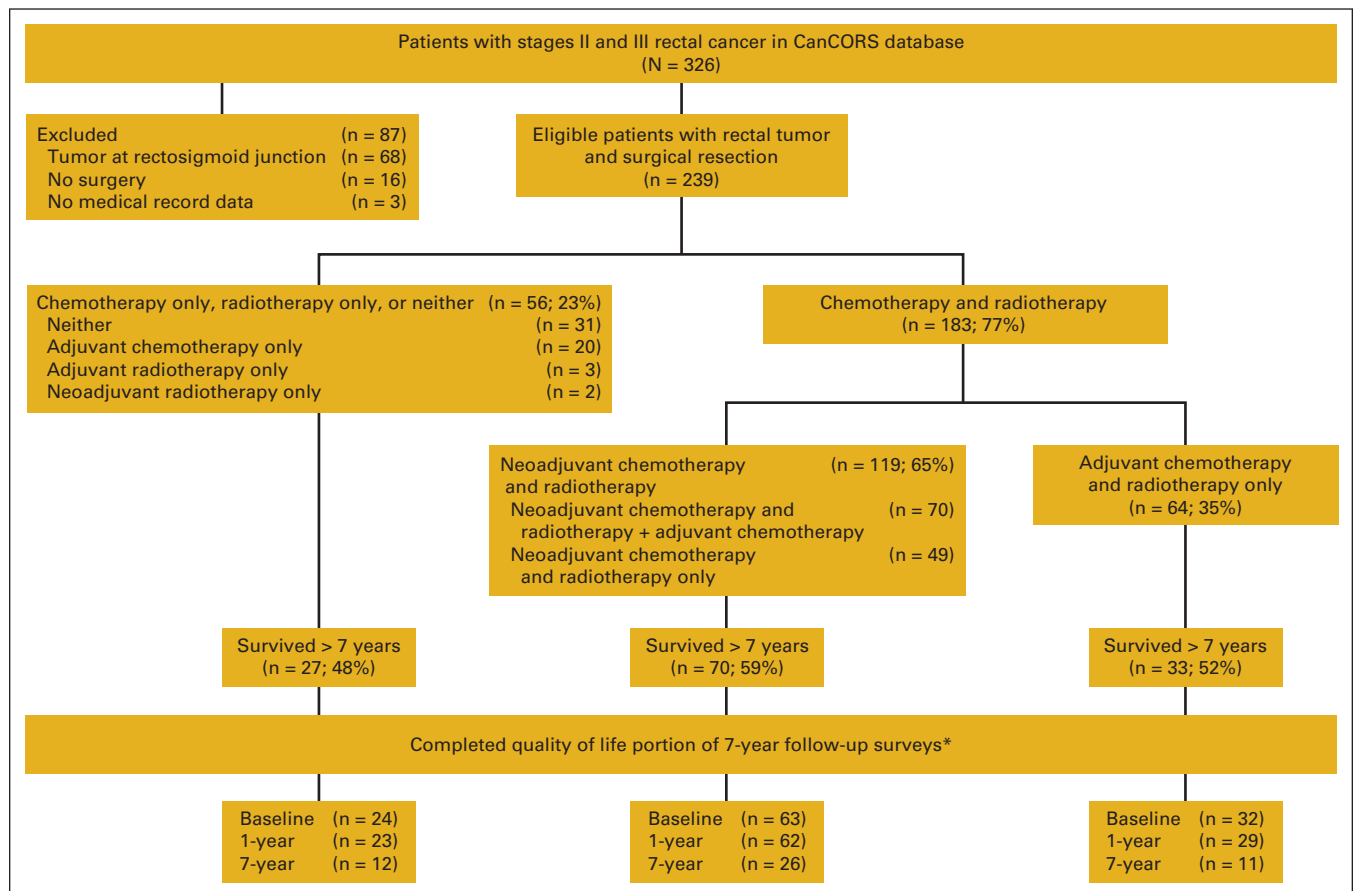
Characteristic (N = 239)	Chemotherapy and Radiotherapy (n = 183; % [No.])	Not Both/Neither* (n = 56; % [No.])	P
1 year before			
Mean	84	75	.02
SD	21	25	
Current health state			
Excellent/very good	39 (71)	41 (23)	.05
Good	35 (64)	30 (17)	
Fair/poor	23 (42)	16 (9)	
Unknown/NA	3 (6)	13 (7)	
Survival			
Alive 1 year after diagnosis	94 (172)	88 (49)	.22
Alive 7 years after diagnosis	56 (103)	48 (27)	.29

Abbreviations: CEA, carcinoembryonic antigen; HMO, health maintenance organization; IQR, interquartile range; MRI, magnetic resonance imaging; NA, not applicable; PET, positron emission tomography; SD, standard deviation; TRUS, transrectal ultrasound; VA, Veterans Affairs.

\* Received chemotherapy only, radiotherapy only, or neither.

ment period, and underwent sphincter-preserving surgery. Although both groups had similar self-reported health ratings at the time of diagnosis, those who received chemoradiotherapy had higher average ratings when asked about their general

health status 1 year before diagnosis. A significantly lower proportion of the group that received chemoradiotherapy was deceased at the time of the baseline survey compared with the group that did not receive both (1% v 7%;  $P = .03$ ; data not



**Figure 1.** Patient flow diagram for the Cancer Care Outcomes Research and Surveillance Consortium (CanCORS) patients with stages II and III rectal cancer. \* Reasons for missing quality-of-life (QOL) scores: baseline (BL): 10 patients had surrogates complete survey, and QOL scores were not available from these surveys; one patient did not answer the QOL questions. 1-year follow-up: 10 refused; four could not be contacted; two did not answer the QOL questions. 7-year follow-up: six patients had advanced disease so did not take the disease-free survivor survey; 33 refused; three incapable of responding; 39 could not be contacted.

shown). However, the difference in the proportions alive 1 year after diagnosis was not significant (94% *v* 88%;  $P = .22$ ).

A higher proportion of those who received only one treatment modality or neither indicated that they had made the decisions themselves (with little or no input from physicians) on whether or not to have chemotherapy and/or radiotherapy, whereas half of those who received chemoradiotherapy reported making the decision to receive these treatments together with their physician. A higher proportion of the group who received chemoradiotherapy indicated that chemotherapy would likely prolong their lives, help with their symptoms, and have adverse effects, and that radiotherapy would likely cure their cancer, prolong their lives, and help with their symptoms as compared with those who received only one or neither treatment modality (Table A1, online only).

Of those who did not receive chemotherapy, 44% reported that no physician ever talked to them about having chemotherapy. Similarly, 41% of those who did not receive radiotherapy said that no physician ever talked to them about having radiotherapy. On the basis of medical record abstraction, 20% of those who did not receive chemotherapy visited a medical oncologist, and 33% of those who did not receive radiotherapy visited a radiation oncologist (results not shown).

After considering all variables in Table 1 and Appendix Table A1, results of multivariable analyses indicated younger age (< 65 years *v*  $\geq$  65 years: odds ratio, 2.49; 95% CI, 1.33 to 4.65) was significantly associated with increased odds of receiving chemoradiotherapy. Preservation of the sphincter was associated with decreased odds of receiving chemoradiotherapy (odds ratio, 0.34; 95% CI, 0.16 to 0.73, results not shown), potentially as a result of surgeons being less likely to refer patients for neoadjuvant chemoradiotherapy when they had higher tumors and sphincter preservation was possible without the need to preoperatively reduce tumor bulk.

### QOL Among Disease-Free Survivors

Of those who survived at least 7 years and completed the QOL and functional status questions at baseline or 1-year follow-up ( $n = 130$ ), 49 (38%) completed the 7-year disease-free follow-up survey; six people who were contacted had advanced disease and therefore took a different survey. There were no significant differences in the demographic or clinical characteristics between those who did and did not complete the 7-year survey, although participants who completed the 7-year survey were marginally more likely to have had at least some college education ( $P = .06$ ) and were enrolled onto the study via a cancer registry versus the VA or an HMO ( $P = .07$ ). We also compared the characteristics of participants who survived at least 7 years with those who did not. Those who survived at least 7 years were significantly younger than those who did not. They also more frequently lived alone, and were enrolled onto the study through an HMO (results not shown).

The adjusted EQ-5D, SF-12, and Defecation Scale scores by time since diagnosis (ie, baseline, 1 year, 7 years) for patients who received chemoradiotherapy compared with those who received only one or neither treatment modality are presented

in Table 2. There were no significant differences in QOL or functional status at any time point except for the SF-12 mental health component score at baseline (ie, 1 to 4 months after diagnosis); those receiving chemoradiotherapy had a significantly lower score than those who received only one treatment modality or neither (43.1 *v* 48.8;  $P = .04$ ). The adjuvant chemoradiotherapy group had significantly worse EQ-5D scores than the neoadjuvant chemoradiotherapy group and the group who received only one or neither treatment modality at 1-year follow-up (0.75, 0.85, 0.85, respectively;  $P = .002, .02$ ), with a similar pattern seen for the SF-12 physical health component score (37.2, 43.3, 45.1, respectively;  $P = .01, .008$ ). There were no significant differences between the three treatment groups in the SF-12 mental health component score or Defecation Scale at any time point.

### Discussion

These results are among the first to illustrate the effects of rectal cancer treatment approach across real-world settings among patients of all ages and states of health, and across several regions of the United States. Our analyses demonstrate that a substantial proportion (23%) of CanCORS patients with stage II/III rectal cancer did not receive chemoradiotherapy. In addition, we found that functional status and QOL were significantly lower 1 year after diagnosis among those who received adjuvant chemoradiotherapy compared with those who received neoadjuvant chemoradiotherapy and only one or neither treatment. Although decreased risk of recurrence, toxicity, and permanent colostomies has previously been demonstrated among patients receiving neoadjuvant chemoradiotherapy,<sup>2,3</sup> the finding that the neoadjuvant therapy group had functional status and QOL scores similar to those of the group that received chemotherapy only, radiotherapy only, or neither may provide a more compelling rationale for adherence to the recommended sequence, given that the group receiving only one or neither therapy would be expected to experience the least long-term effects from treatment.

Our findings with respect to the proportion of patients receiving recommended therapy were consistent with previous evaluations of SEER data,<sup>5,6,9</sup> which found that 30% to 40% of patients with stage II/III rectal cancer did not receive any radiotherapy, and that younger age was associated with receipt of radiotherapy. These studies included earlier years of data before wider uptake of NCCN guidelines for neoadjuvant chemoradiotherapy, which may explain why their estimates of radiotherapy nonreceipt are somewhat higher. Of the group that received only chemotherapy, only radiotherapy, or neither, 73% had no or mild comorbidities, 88% were still alive 1 year after diagnosis, and almost no patients reported that they expected to die in less than 5 years. Therefore, it does not seem that lack of therapy in most cases was simply a result of imminent death or patients being too ill to receive chemotherapy and/or radiotherapy. The association between nonsphincter-preserving surgery and receipt of chemoradiotherapy may suggest that some surgeons predominantly refer patients with lower-lying tumors for chemoradiotherapy in an attempt to



**Table 2.** Adjusted Functional Status, QOL, and Defecation Scale Scores by Treatment and Time Since Diagnosis Among Those Who Survived at Least 7 Years and Completed at Least One QOL Survey\*

Scales	Chemotherapy and Radiotherapy			Chemotherapy Only, Radiotherapy Only, or Neither		
	BL (n = 95)	1 Year (n = 91)	7 Years (n = 37)	BL (n = 23)	1 Year (n = 27)	7 Years (n = 12)
EQ-5D	0.85	0.79	0.64	0.88	0.82	0.72
SF-12						
Physical health	36.2	40.5	37.9	39.0	44.5	37.9
Mental health	43.1†	51.1	51.8	48.8†	54.9	52.2
Defecation Scale‡	66.9	71.5	68.8	73.7	68.4	75.8

Scales	Neoadjuvant Chemotherapy and Radiotherapy			Adjuvant Chemotherapy and Radiotherapy			Chemotherapy Only, Radiotherapy Only, or Neither		
	BL (n = 63)	1 Year (n = 62)	7 Years (n = 26)	BL (n = 32)	1 Year (n = 29)	7 Years (n = 11)	BL (n = 23)	1 Year (n = 27)	7 Years (n = 12)
EQ-5D	0.81	0.85†	0.66	0.78	0.75†	0.61	0.83	0.85†	0.72
SF-12									
Physical health	35.4	43.3†	37.9	36.9	37.2†	34.1	40.0	45.1†	36.5
Mental health	46.7	48.5	52.0	44.9	46.5	51.2	49.9	49.0	52.2
Defecation Scale	64.9	70.3	58.2	60.1	73.0	80.1	72.5	68.4	75.2

Abbreviations: BL, baseline; EQ-5D, EuroQoL-5D; QOL, quality of life; SF-12, Short Form-12.

\* All factors in Table 1 and Appendix Table A1 were candidates for the models, plus corresponding baseline scores.

† Significant difference between groups, *P* < .05.

‡ Defecation Scale only administered to patients who received sphincter-preserving surgery; n = 57 responded at baseline, n = 70 at 1 year, and n = 32 at 7-year follow-up.

save the sphincter, and do not consistently refer patients with higher tumors.

More than 40% of patients who did not receive chemoradiotherapy reported that no physician ever discussed the possibility of chemotherapy or radiotherapy with them, and medical record data confirmed that 70% to 80% did not visit an oncologist. It is possible that those who did not visit an oncologist refused to engage in a discussion about these therapies or did not recall that a different type of physician had spoken with them about it. However, given the high percentage of patients who did not have medical record data indicating a visit to an oncologist, it is also possible that the ideal multidisciplinary approach to treatment planning for patients with rectal cancer was not executed in the majority of these patients who did not receive chemotherapy and radiotherapy, and that no one fully described the treatment options and benefits to these individuals. Among the 27 (48%) members of the group who did not receive both chemotherapy and radiotherapy and survived at least 7 years, it is likely that they would not have gained benefit from additional neoadjuvant or adjuvant therapy. However, the 52% who did not survive that long may have benefitted. It is not currently possible to precisely predict at diagnosis who will and will not benefit from neoadjuvant chemoradiotherapy, which is why NCCN guidelines recommend it for nearly all patients with stage II/III disease.

It should also be noted that a significantly higher percentage of patients not receiving chemoradiotherapy reported that they had made the decision concerning whether or not to receive therapy, as opposed to making the decision together with their physician or their physician alone making the decision. It is

possible that this is indicative of strong patient preference and deference to patient autonomy on the part of the physician, or alternatively, may indicate ineffective physician communication regarding the risk/benefit ratio for these treatments and/or a lack of data clearly indicating their benefit.

Although the results indicated that there was no difference in QOL at any time point between those who received chemoradiotherapy and those who did not, except for the SF-12 mental health component score at baseline, the stratified analysis by chemotherapy-radiotherapy-surgery sequence demonstrated that those receiving adjuvant chemoradiotherapy had lower EQ-5D and SF-12 physical health component scores 1 year after diagnosis after adjusting for baseline scores and other covariates. Statistically significant differences also fell within previously reported minimal clinically important difference ranges for the EQ-5D and SF-12.<sup>36-40</sup> There were no other significant differences among groups at the follow-up time points. Two other long-term follow-up studies found that patients receiving neoadjuvant radiotherapy reported fewer bowel movements compared with patients receiving adjuvant radiotherapy,<sup>12,13</sup> but did not find differences in overall functional status or QOL.<sup>13</sup> It is possible that the main benefits of neoadjuvant chemoradiotherapy compared with adjuvant chemoradiotherapy occur in the short term, and that over time, the effects of any treatment for rectal cancer on QOL become more similar.

A potential limitation of this study is that self-reported information may have been collected before oncologist visits and treatment discussions with other providers. However, the fact that both medical record and self-report data could be used and compared for variables such as oncologist visits was a strength of

this study. We also do not have information on whether patients were discussed in a Tumor Board or other multidisciplinary setting. Another potential limitation is the possibility of confounding by unmeasured characteristics that may have differed between treatment groups such as exact location of the tumor, hospital type/size, specialty of the surgeon, and other provider characteristics. Finally, small sample size, especially at the point of 7 years after diagnosis as a result of loss to follow-up or death, reduced statistical power for some subgroup analyses, and we were unable to stratify on the basis of specific chemotherapy drugs, chemotherapy and radiotherapy dosage, and exact timing of administration to determine complete compliance with guidelines.

In conclusion, the majority of patients with stage II and III rectal cancer received chemoradiotherapy, but a substantial proportion of patients did not. It is possible that patient preferences or proximal tumor location explain some of this variation, but on the basis of the finding that patients often reported not being told of these therapies, it is questionable whether or not many patients were given the opportunity to learn more about treatment options directly from oncologists. Among patients who did receive chemoradiotherapy, those who received guideline-recommended neoadjuvant therapy had the best QOL and physical health scores 1 year later. Further evaluation of patient and provider reasons for not pursuing recommended neoadjuvant chemoradiotherapy is necessary to determine how and where to target process improvements and education to ensure that patients have access to recommended treatments. More immediately, ensuring that patients have an opportunity to have a thorough, individualized discussion regarding chemoradiotherapy before surgery would also likely increase receipt of guideline-concordant care.

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Appendix

Table A1. Patient Beliefs and Treatment Preferences

Preference or Belief	Chemotherapy and Radiotherapy (n = 183; %, [No.])	Not Both/ Neither* (n = 56; %, [No.])	P
Patient role in decision making about therapies†‡§ (4 missing responses; 40 not asked¶)			
Decision to have chemotherapy			
Patient made decision	32 (52)	52 (17)	.02
Patient made decision together with physician	50 (81)	33 (11)	
Physicians made decision	17 (27)	15 (5)	
Do not know	1 (2)	0 (0)	
Decision to have radiotherapy			
Patient made decision	35 (58)	47 (14)	< .01
Patient made decision together with physician	50 (83)	30 (9)	
Physicians made decision	12 (19)	17 (5)	
Do not know	3 (5)	7 (2)	
Patient beliefs about therapies†‡§ (chemotherapy: 46 not asked¶; 4 missing; radiotherapy: 45 not asked¶; 3 missing)			
Chemotherapy (“very likely” or “somewhat likely”)			
Would likely cure their cancer	69 (111)	56 (15)	.24
Would likely prolong their life	88 (142)	59 (16)	< .01
Would likely help with their symptoms	77 (109)	50 (12)	.02
Would likely have side effects	86 (140)	67 (18)	.03
Radiotherapy (“very likely” or “somewhat likely”)			
Would likely cure their cancer	61 (101)	32 (8)	.03
Would likely prolong their life	80 (133)	36 (9)	< .01
Would likely help with their symptoms	70 (105)	41 (9)	.05
Would likely have side effects	71 (118)	52 (13)	.06
Role patient generally prefers to play in decision making and role family played†§ (5 missing)			
Preferred role			
Patient make decision on his/her own	32 (49)	39 (16)	.82
Make the decision together with physician	58 (89)	51 (21)	
Physicians make the decision	10 (15)	10 (4)	
Role family played			
Patient made decision	45 (68)	50 (19)	.81
Make the decision together with family	53 (81)	47 (18)	
Family made decision	2 (3)	3 (1)	
Preferences regarding extension of life†§ (5 missing)			
Extension of life v pain and discomfort			
Prefers treatment that extends life as much as possible, even if it means having more pain/discomfort	53 (82)	32 (13)	.09
Prefers treatment that focuses on relieving pain as much as possible, even if it means not living as long	35 (54)	51 (21)	
Refused to answer/do not know	12 (19)	17 (7)	
Extension of life v cost of treatment			
Prefers treatment that extends life as much as possible, even if it means using up financial resources	63 (97)	49 (20)	.25
Prefers treatment that costs less, even if means not living as long	26 (41)	32 (13)	
Refused to answer/do not know	11 (17)	19 (8)	

continued on next page

Table A1. (continued)

Preference or Belief	Chemotherapy and Radiotherapy (n = 183; %, [No.])	Not Both/ Neither* (n = 56; %, [No.])	P
Expected time to live, fatalism beliefs, and concerns about treatment†			
Expected time to live			
Less than 5 years	4 (6)	6 (2)	.88
At least 5 years	62 (84)	64 (21)	
In God's hands/do not know	34 (46)	30 (10)	
Fatalism beliefs ("strongly agree" or "agree")			
When bad things happen, we are not supposed to know why, we are just supposed to accept them	40 (57)	53 (18)	.34
People die when it is their time, and nothing can change it	62 (87)	56 (19)	.30
Everything that happens is a part of God's plan	76 (107)	71 (24)	.50
If bad things happen, it is because they were meant to be	44 (62)	44 (15)	.74
Treatment concerns ("very worried" or "somewhat worried") about:			
Adverse effects from treatment	63 (87)	53 (18)	.26
Cost of treatment	21 (29)	26 (9)	.81
Taking time away from family	33 (46)	41 (14)	.80
Taking time away from work	32 (44)	44 (15)	.76
Transportation to treatment	13 (18)	14 (5)	.45

\* Received chemotherapy only, radiotherapy only, or neither.

† Full survey.

‡ Brief survey.

§ Survey of surrogate (live patient).

|| Survey of surrogate (deceased patient).

¶ Items not asked of those reporting that no one ever talked to them about chemotherapy/radiotherapy, or that they were told not to have it.