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Patient and physician preferences for surgical and adjuvant treatment options for rectal cancer

Abstract

Hypothesis Patients and their clinicians hold varying preferences for surgical and adjuvant treatment therapies for rectal cancer.

Design Preferences were determined using the Prospective Measure of Preference.

Setting Royal Prince Alfred and St Vincent's hospitals in Sydney, Australia.

Participants Patients with colorectal cancer were interviewed during their postoperative hospital stay, and physicians were asked to complete a mailed survey.

Main Outcome Measures The Prospective Measure of Preference method produces 2 outcome measures of preference: willingness to trade and prospective measure of preference time trade-off.

Results Patients' strongest preference was to avoid a stoma: more than 60% would give up a mean of 34% of their life expectancy to avoid this surgical option. This was followed by treatment options involving chemoradiotherapy, where more than 50% would give up a mean of almost 25% of their life to avoid treatment. Surgeons held stronger preferences against all adjuvant options compared with oncologists ($P \le .01$).

Conclusions Patients had strong preferences against all treatment options, and these preferences frequently differed from those of physicians. These results highlight the importance of determining patients' own preferences in the clinical encounter. Furthermore, the diversity of preferences of clinical subspecialists emphasizes the need for multidisciplinary treatment planning to ensure a balanced approach to treatment decision making for patients with rectal cancer.

Disciplines

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Patient and Physician Preferences for Surgical and Adjuvant Treatment Options for Rectal Cancer

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Conclusions: Patients had strong preferences against all treatment options, and these preferences frequently differed from those of physicians. These results highlight the importance of determining patients' own preferences in the clinical encounter. Furthermore, the diversity of preferences of clinical subspecialists emphasizes the need for multidisciplinary treatment planning to ensure a balanced approach to treatment decision making for patients with rectal cancer.

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use of adjuvant therapy for patients with rectal cancer. This controversy has led to distinct variations in clinical practice guidelines and practice patterns across the world.1-3 European trials and large metaanalyses have demonstrated that preop-Author Affiliations: Surgical erative and postoperative radiotherapy improves local recurrence rates,4-8 and in 1 significant Swedish trial,4 preoperative treatment improved overall long-term and cancer-specific survival.

Although the results of randomized trials are encouraging and help guide physicians, contention stems from the fact that many of the reported data relate to treatments administered up to 15 years ago, when surgical techniques would be considered suboptimal by today's standards. Therefore, it is argued that if surgery were optimized using current total mesorectal excision techniques, radiotherapy may not necessarily be indicated.9-11 This view,

however, is not supported by evidence from the Dutch total mesorectal excision trial,5 where total mesorectal excision was mandated but the addition of neoadjuvant radiotherapy still resulted in reduced rates of local recurrence, albeit with no improvement in 5-year survival.

Although the potential benefits of radiotherapy have been disputed, the adverse effects are well recognized and may outweigh any advantages. Many patients will develop permanent bowel problems greater than the normal rate of surgical adverse effects, 12 with short-term effects also increased for patients receiving radiotherapy. 13,14 A particular concern associated with postsurgical irradiation to the bowel is the potential for irreversible damage that patients must live with for the remainder of their lives.

There are, however, strong indications that combining postoperative radiotherapy with concomitant chemotherapy for stages II and III (T3-4, N0-1, M0) disease improves local recurrence and dis-

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OR MORE THAN A DECADE, A

debate has surrounded the

tant metastases. 15,16 Currently, efforts are being directed at investigating the effects of combination therapy in the preoperative setting, which are not as well defined. One recent study¹⁷ concluded that after 5 years of follow-up, preoperative compared with postoperative combination therapy improved local control and was associated with reduced toxic effects, thus enhancing the therapeutic ratio. Again, any possible benefits must be weighed against adverse effects. To the adverse effects of radiotherapy are added further acute complications associated with chemotherapy.

Given the lack of consensus about the role of adjuvant therapy in rectal cancer and the quality-of-life implications, patients' own preferences or values for each different treatment combination and outcome should become a key component of clinical decision making and informed consent. Therefore, this study was undertaken to assess patients' own preferences for different treatment options for rectal cancer and to compare these preferences with those of colorectal surgeons and medical and radiation oncologists answering as if they themselves were patients with rectal cancer (patient surrogates).

METHODS

Verbal scripts were developed to explain 5 treatment scenarios for locally advanced rectal cancer (T3-4, N0-1, M0; stage II-III) in a standardized manner. These scenarios were chosen because of difficulties balancing differential benefits and harms of each treatment. Information was based on the most current evidence available. For all the scenarios, a low anterior resection (AR) was used as the standard comparator. The 5 treatment choices were (1) low AR compared with low AR plus postoperative radiotherapy, (2) low AR compared with low AR plus preoperative radiotherapy, (3) low AR compared with low AR plus chemotherapy, (4) low AR compared with low AR plus chemoradiotherapy, and (5) low AR compared with abdominoperineal resection (APR). The final scenario was included to enable patients' preferences for each adjuvant option to be compared with what has been documented consistently as a surgical procedure that patients prefer to avoid. 18,19

PROSPECTIVE MEASURE OF PREFERENCE

During a face-to-face interview, each treatment scenario, including the benefits, risks, and likely long-term outcomes, was described. Once the patient had reached a level of understanding sufficient to make an informed treatment choice, patient preferences were elicited using the Prospective Measure of Preference method. 18,19 Patients were asked how much of their remaining life expectancy they would be willing to trade (give up) to avoid each adjuvant therapy or an APR. The Prospective Measure of Preference method produces 2 measures of preference. The first measure is a dichotomous variable (yes/no) of willingness to trade (WTT) any life expectancy to avoid the nonstandard therapy and is summarized as the proportion of the group overall that would be willing to trade. The second measure, a prospective measure of preference time trade-off (PMPt), is summarized as the mean proportion of remaining life expectancy traded. Previous studies have demonstrated a PMPt range of 0 to 0.11.18 A PMPt greater than 0.10 is a measure of a strong preference against treatment. The patient questionnaire also obtained demographic and clinical information (age, sex, country of birth, language spoken at home, educa-

tional level, marital and employment status, number of dependents, preoperative therapy, site of primary cancer, surgical procedure, and stage of disease).

DEVELOPMENT OF QUESTIONNAIRE FOR PHYSICIANS

The same questionnaire was adapted to a self-administered format to be mailed to physicians. Physicians were asked to respond as if they themselves were patients with rectal cancer (surrogate patients).

VALIDATION OF QUESTIONNAIRES

The questionnaires were pilot tested to confirm test-retest reliability and the effect of format (face-to-face or written) on responses. Thirty clinical staff and 10 patients each completed the questionnaire on 2 occasions, 1 week apart, with the format (written or verbal) in random order.

PATIENT RECRUITMENT AND INCLUSION AND EXCLUSION CRITERIA

Patients with colorectal cancer (Duke stages A-C) admitted to 2 teaching hospitals for curative surgery were eligible to participate. Patients who were cognitively impaired, who were deemed too unwell by their treating physician, or who were emergency admissions were considered ineligible. For non-English-speaking patients, an interpreter was arranged through the hospital interpreter service. Under ethical guidance, all the patients were interviewed within a few days of surgery and at a time before pathology results were available or definitive postoperative treatment plans had been decided. A previous study¹⁸ highlighted that patient preferences remained stable from the preoperative to the postoperative period.

SPECIALIST PHYSICIAN RECRUITMENT

All members of the Colorectal Surgical Society of Australasia (colorectal surgeons) and the Medical Oncology Group of Australia (medical oncologists) and radiation oncologists of the Royal Australian and New Zealand College of Radiologists were surveyed. Physicians were considered ineligible if they were not practicing medicine, were on extended leave of more than 6 weeks, or were no longer resident in Australia. Two reminder letters were sent to nonrespondents. Institutional ethics committee approval was obtained for the study to proceed.

STATISTICAL ANALYSIS

Statistical analysis was performed blind to participants' group status (patient, surgeon, or radiation or medical oncologist). For each scenario, WTT was compared between groups using χ^2 tests, whereas the PMPt was compared using Wilcoxon rank sum tests. Within-group WTT and PMPt were compared between scenarios using McNemar tests or Wilcoxon signed rank tests as appropriate. Results were compared in patients with colon vs rectal cancer. Independent predictors of WTT responses were assessed using logistic regression modeling. Potential predictors included in the model were those exhibiting $P \le .25$ in univariate analysis, 20 and these were then sequentially eliminated using a backward, stepwise approach until all remaining predictors were significant (P < .05). Analysis was performed using a software program (SPSS; SPSS Inc, Chicago, Illinois).

SAMPLE SIZE

The WTT ranged from 0.20 to 0.54 across scenarios in a previous colorectal study. 18 Assuming a similar distribution, 100 patients would be needed to estimate the PMPt, with 95% confidence intervals of $\pm 9\%$. To detect at least a 10% difference in the mean PMPt, at least 36 participants were needed per group to achieve a power of 80% at a significance level of .05 assuming a 15% standard deviation of preference scores as reported previously. 18

RESULTS

VALIDATION OF QUESTIONNAIRES

Test-retest comparisons of WTT and PMPt were highly correlated (R=0.72-0.96) for all but 1 scenario for 1 group. The impact of format did not affect responses, with strong correlations (R=0.83-0.97) for all but 1 scenario for 2 pilot groups.

RESPONSE RATE

Of 200 patients with colorectal cancer admitted to Royal Prince Alfred Hospital, 103 were ineligible to participate (11 had clinical contradictions, 27 had metastatic disease, 14 did not have an appropriate interpreter available, 9 were too unwell, 3 had died, 1 family refused access, 20 were cognitively impaired, 4 were discharged early, and 14 were missed/emergency admissions/not seen by clinical nurse specialist), and 22 patients refused. Of the 97 eligible patients, 75 consented to be interviewed (77% consent rate). A further 28 patients were recruited from St Vincent's Hospital. Patients were recruited during their postoperative hospital stay. Response rates to the mailed survey were 79% (87 of 110) for colorectal surgeons, 47% (97 of 206) for radiation oncologists, and 47% (80 of 169) for medical oncologists. Characteristics of the patients are given in **Table 1**. The mean age of the patients was 65 years (range, 26-88 years).

PROSPECTIVE MEASURE OF PREFERENCE OUTCOMES

Patient Preferences

Patient preferences are given in **Table 2**. Patients' strongest preference was to avoid a stoma, with almost 65% (WTT=0.63) of the group giving up a mean of 34% (PMPt=0.34) of their life expectancy to avoid this option. This was found to be significantly higher than for all other scenarios (Wilcoxon signed rank tests, $P \le .003$). The lowest preference scores (WTT = 0.43; PMPt = 0.17) were found for preoperative radiotherapy. For 2 of the remaining options, postoperative radiotherapy and chemoradiotherapy, patients who indicated a preference against treatment did so to a large degree, as reflected by high PMPt scores. For chemoradiotherapy, the mean amount of life traded to avoid this treatment (PMPt=0.24) was significantly higher than that for any other adjuvant treatment options (all Wilcoxon signed rank tests, $P \le .03$).

Table 1. Characteristics of the 103 Study Patients

ariable Patients, No	
Sex	
Male	58 (56)
Female	45 (44)
Cancer site	
Colon	49 (48)
Rectum	54 (52)
Stage	
A	19 (18)
В	35 (34)
С	37 (36)
D^{a}	2 (2)
Nonmalignant neoplasm ^a	10 (10)
Country of birth	
Australia	67 (65)
Other	36 (35)
Language	
English	88 (85)
Other	15 (15)
Type of surgery	
Anterior resection	59 (57)
Abdominoperineal resection	6 (6)
Colectomy	30 (29)
Hartmann procedure	1 (1)
Transanal excision	2 (2)
Other	5 (5)
Preoperative treatment	
None	87 (84)
Radiotherapy	11 (11)
Chemoradiotherapy	5 (5)

^a Pathologic abnormality determined after interview.

Table 2. Patient Preferences for AR and Alternative Treatment Options

Treatment Option	Patients, No.	WTT	Mean PMPt
AR vs AR + postoperative radiotherapy	101	0.52	0.20
AR vs AR + preoperative radiotherapy	99	0.43	0.17
AR vs AR + chemotherapy	101	0.60	0.20
AR vs AR + chemoradiotherapy	100	0.52	0.24
AR vs abdominoperineal resection	99	0.63	0.34

Abbreviations: AR, anterior resection; PMPt, prospective measure of preference time trade-off; WTT, willingness to trade.

Patients With Rectal vs Colon Cancer

For all the scenarios, the mean PMPt values were significantly lower for patients with rectal cancer vs colon cancer. Patients with colon cancer, therefore, indicated a stronger aversion to adjuvant treatment than those with rectal cancer. Avoidance of a stoma was a stronger preference of both groups.

Predictors of Patient Preferences

Independent predictors of WTT are given in **Table 3**. A higher level of education predicted WTT for both radiotherapy options, that is, a stronger preference against adjuvant radiotherapy. After adjusting for level of edu-

Table 3. Patient Preferences: Independent Predictors of Willingness to Trade

Independent Predictor	Multivariate Association AOR (95% CI)
Treatment Option: AR + Postopera	ative Radiotherapy
Educational level	
Primary to year 10	1 [Reference]
High school and tertiary	2.61 (1.14-6.02)
Cancer site	
Rectum	1 [Reference]
Colon	2.91 (1.26-6.72)
Treatment Option: AR + Preopera	ntive Radiotherapy
Educational level	
Primary to year 10	1 [Reference]
High school and tertiary	4.70 (1.80-12.27
Cancer site	
Rectum	1 [Reference]
Colon	4.71 (1.67-10.38
Treatment Option: AR + Ch	emotherapy
Postoperative treatment accepted	
No	1 [Reference]
Yes	0.27 (0.08-0.90)
Preoperative treatment accepted	
No	1 [Reference]
Yes	0.23 (0.07-0.76)
APR	
Relative/friend has stoma	
No	1 [Reference]
Yes	4.78 (1.68-13.74
Relative/friend had radiotherapy	
No	1 [Reference]
Yes	0.15 (0.05-0.43)

Abbreviations: AOR, adjusted odds ratio; APR, abdominoperineal resection; AR, anterior resection; CI, confidence interval.

cation, patients with colon cancer were significantly more likely than those with rectal cancer to trade, indicating greater aversion to radiotherapy. For the option involving chemoradiotherapy, patients who had undergone preoperative treatment were less likely to trade life expectancy to avoid this treatment. Furthermore, patients who knew a relative or friend who had had an APR and lived with a stoma were more likely to indicate a preference against this surgical option.

Subspecialty Preferences

Physicians' preferences are given in **Table 4**. The statistical significance of differences between groups is given in **Table 5**. Patient and physician preferences were consistently different for the scenario involving an APR, with patients exhibiting significantly stronger preferences to avoid this surgical option. Colorectal surgeons' greatest preference was to avoid postoperative radiotherapy (WTT=0.91; PMPt=0.25), whereas radiation oncologists were less likely to trade, indicating less of an aversion toward this option. High proportions of radiation and medical oncologists were willing to trade to avoid each treatment; however, the actual amount of years given up ranged from 5% to 8% (PMPt=0.05-0.08), which was much less than for surgeons and patients. Surgeons and

Table 4. Physician Preferences for AR and Alternative Treatment Options

Treatment Option and Group	Patients, No.	WTT	Mear PMP
To avoid AR + postoperative radiotherapy			
Colorectal surgeons	87	0.91	0.25
Radiation oncologists	76	0.60	0.05
Medical oncologists	96	0.74	0.08
To avoid AR + preoperative radiotherapy			
Colorectal surgeons	85	0.79	0.12
Radiation oncologists		0.53	0.05
Medical oncologists	94	0.71	0.06
To avoid AR + chemotherapy			
Colorectal surgeons	85	0.72	0.11
Radiation oncologists	85	0.70	0.08
Medical oncologists	96	0.69	0.05
To avoid AR + chemoradiotherapy			
Colorectal surgeons	85	0.79	0.14
Radiation oncologists	76	0.64	0.08
Medical oncologists	95	0.72	0.07
To avoid abdominoperineal resection			
Colorectal surgeons	86	0.72	0.15
Radiation oncologists	78	0.79	0.14
Medical oncologists	95	0.88	0.14

Abbreviations: AR, anterior resection; PMPt, prospective measure of preference time trade-off; WTT, willingness to trade.

radiation oncologists consistently expressed divergent preferences for options that involved radiotherapy, with surgeons being more averse.

COMMENT

This study demonstrates that patients hold varying preferences for surgical and adjuvant therapy options for rectal cancer and that these preferences often do not correspond with the preferences of colorectal surgeons and oncologists answering as if they were patients themselves. All clinical subspecialties surveyed indicated strong preferences against all options presented to them. Furthermore, the amount of survival that patients and specialists were willing to forsake to avoid adjuvant treatment was often greater than or comparable with the survival advantages documented in randomized controlled trials corresponding to the clinical scenarios presented.

As expected, patients were most averse to an APR, with many willing to trade life expectancy in substantial amounts to avoid this surgical option. The extent to which patients were averse to this surgery was much greater than anticipated compared with previous studies in colorectal cancer and Crohn disease. Patients were significantly more likely to be averse to an APR if they had known or knew a patient with a stoma. This particular association, to our knowledge, has not been previously reported and may be a result of the negative experiences encountered by people living with a stoma in the community. 21,22

For all the adjuvant scenarios, patients who indicated a preference against treatment did so with a strong degree of certainty, as shown by the large proportions of life they would give up (PMPt=0.17-0.24). Previous studies of colorectal conditions^{18,19} have indicated that a PMPt greater

than 0.10 is a measure of a strong preference; therefore, for these adjuvant options, patients expressed particularly strong views. The large amount of life patients were willing to give up to avoid treatment is also significant considering the elderly demographic of this patient group. Patients would more likely trade to avoid options involving chemotherapy. This finding is consistent with a previous study¹⁸ exploring patient views of treatment for colon cancer and most probably reflects concerns for the effects of treatment on quality of life.

The results of this study suggest that if patients are offered adjuvant therapy they would most likely opt for preoperative radiotherapy. From a patient's perspective it is plausible that preoperative treatment may be viewed as a more favorable option because of its relatively short duration compared with other regimens and the fact that treatment may be complete once surgery has been performed. Furthermore, any potential damage to the bowel due to presurgical irradiation is likely to be removed during surgery, which is appealing from a quality-of-life perspective. The preference for preoperative treatment may also be a reflection of coping style among patients whereby those who have a problem-focused coping style may prefer to "get all the treatment over with" as quickly as possible. ^{23,24}

In this study, patients with rectal cancer were more willing to accept all adjuvant treatment options, as indicated by lower WTT and PMPt values, compared with patients with colon cancer. Furthermore, the site of cancer was found to be an independent predictor of preference for both radiotherapy options. This finding highlights that the choices and values of patients who are actually facing the treatment decisions differ from those who are not. Although some of this variation can be explained by cognitive dissonance reduction²⁵ in the group of patients with rectal cancer who had preoperative treatment (n=11), this cannot explain all the difference. These findings have important methodological implications for future studies and emphasize the importance of recruiting actual patients to quantify preferences.

Specialists' preferences were generally significantly higher than those of patients, particularly among surgeons. Differences in preferences between patients and physicians are not uncommon, and this finding is consistent with other studies in colorectal, 18 breast, 26 and prostate cancer²⁷ and end-of-life decisions.²⁸ Concordance of 50% to 80% has been reported,27 and it has been shown that predictions of treatment preferences more closely resemble the views of the surrogate than the actual preferences of the individual facing treatment. Although it is acknowledged that physicians have to make decisions for their patients on an individual basis, such discordance may have implications for clinical decision making and patient referral pathways. Specialist treatment recommendations remain an important predictor of treatment choice, with patients likely to ask their physicians for the treatment they would prefer. 29,30 The present study suggests that surgeons acting as patient surrogates would be less likely to recommend adjuvant therapy. It is also plausible that such strongly held preferences may affect the likelihood that surgeons refer their patients to oncology consultations. These attitudes may partially explain why

Table 5. Statistical Significance of Differences Between Patients, Surgeons, and Radiation and Medical Oncologists for Alternative Treatment Options^a

Comparison Group	WTTb	PMPt
To avoid AR + postoperative radiotherapy		
Patients vs colorectal surgeons	<.001	.01
Patients vs radiation oncologists	.16	.03
Patients vs medical oncologists	<.001	.26
Colorectal surgeons vs radiation oncologists	<.001	<.00
Colorectal surgeons vs medical oncologists	.01	<.00
Radiation vs medical oncologists	.09	.16
To avoid AR + preoperative radiotherapy		
Patients vs colorectal surgeons	<.001	.07
Patients vs radiation oncologists	.18	.30
Patients vs medical oncologists	<.001	.74
Colorectal surgeons vs radiation oncologists	<.001	<.00
Colorectal surgeons vs medical oncologists	.14	<.00
Radiation vs medical oncologists	.02	.02
To avoid AR + chemotherapy		
Patients vs colorectal surgeons	<.001	.62
Patients vs radiation oncologists	<.001	.99
Patients vs medical oncologists	.001	.54
Colorectal surgeons vs radiation oncologists	.84	.51
Colorectal surgeons vs medical oncologists	.52	.00
Radiation vs medical oncologists	.67	.01
To avoid AR + chemoradiotherapy		
Patients vs colorectal surgeons	<.001	.94
Patients vs radiation oncologists	.08	.11
Patients vs medical oncologists	<.01	.17
Colorectal surgeons vs radiation oncologists	.04	<.01
Colorectal surgeons vs medical oncologists	.23	.00
Radiation vs medical oncologists	.35	.87
To avoid abdominoperineal resection		
Patients vs colorectal surgeons	.26	<.01
Patients vs radiation oncologists	.03	.01
Patients vs medical oncologists	<.001	.01
Colorectal surgeons vs radiation oncologists	.26	.40
Colorectal surgeons vs medical oncologists	<.01	.11
Radiation vs medical oncologists	.11	.46

Abbreviations: AR, anterior resection; PMPt, prospective measure of preference time trade-off; WTT, willingness to trade.

currently in Australia there is less than 40% concordance with 2 national clinical guidelines that recommend the use of adjuvant treatment for some patients with rectal cancer.³¹

A limitation of this study is the low response rates from oncologists. Each of the societies surveyed has a broad membership base, so the survey was likely mailed to physicians with little interest in or experience with rectal cancer. However, previous studies¹⁸ involving these groups have reported similar response rates, with respondents most likely interested in gastrointestinal tract disorders. This study also was performed before the Swedish Rectal Cancer Trial⁴ reported long-term survival benefits, so these data could not be included in the treatment scenarios. However, the issues of optimal surgical techniques and the impact of treatment on quality of life remain unresolved.

In conclusion, patients and physicians were able to trade life expectancy to indicate a preference for various

^a Test statistics are available from the authors on request.

b P value for χ^2 test.

^c P value for Wilcoxon rank sum test.

adjuvant and surgical options for rectal cancer. Patients had strong preferences against all treatment options, and they frequently differed from those of physicians. These results highlight the importance of determining patients' own preferences in the clinical encounter. Furthermore, the diversity of preferences of clinical subspecialists emphasizes the need for multidisciplinary treatment planning to ensure a balanced approach to treatment decision making for patients with rectal cancer.

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