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Glenn P. Salkeld
University of Wollongong, gsalkeld@uow.edu.au

Michael J. Solomon
University of Sydney

Leonie Short
Queensland University of Technology

Phyllis N. Butow
University of Sydney

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Abstract

Objectives: To determine which aspects of the treatment decision process, therapy and outcomes are most important to patients with colorectal cancer (CRC). Design: Cross-sectional survey. Participants: A total of 102 men and 73 women who had completed primary treatment for CRC in two teaching hospitals in Central Sydney, Australia. Main outcomes measures: Patient's rating of the importance of the decision-making aspects and outcomes of treatment for CRC. Results: Trust in their surgeon and confidence of specialty training are of paramount importance to CRC patients. Patients also have a strong desire to get on with treatment quickly and rate the risk of disease recurrence and quality of life as being very important in their treatment decisions. Gender, age and whether the patient had undergone adjuvant radiotherapy were all significant predictors of preferred mode of treatment decision-making. Fifty-eight per cent of women preferred a shared decision-making role compared with 36% of men, whilst older patients and those who had undergone adjuvant radiotherapy were significantly more likely to prefer that their surgeon decide upon treatment when compared with younger patients and respondents who have not had radiotherapy. Conclusions: Regardless of whether a patient prefers an active or more passive role in decision-making, having a surgeon explain treatment options in a clear, unhurried and open manner is vital to how patients feel about their treatment. Whilst acknowledging that individual patients will have different needs for information and preferences for treatment, there are several factors amongst many in the process of decision-making which are considered very important by patients with CRC. A surgeon who adopts a consultation style that is open and informative, that offers patients the chance to participate in the process of decision-making and clearly explain treatment options and outcomes will engender trust with their patient.

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A matter of trust – patient's views on decision-making in colorectal cancer

Glenn Salkeld B Bus GDip Health Econ MPH PhD,* Michael Solomon MSc (Clin Epi) FRACS,† Leonie Short MHP AFCHSE‡ and Phyllis N Butow BA (Hons) Dip Ed M Clin Psych MPH PhD§

*Senior Lecturer, School of Public Health and Surgical Outcomes Research Centre (SOuRCe), The University of Sydney, NSW, †Associate Professor, Department of Colorectal Surgery and Surgical Outcomes Research Centre (SOuRCe), The University of Sydney, NSW, ‡Honorary Research Fellow, Centre for Public Health, Queensland University of Technology, Kelvin Grove, Queensland and §Associate Professor, Medical Psychology Unit and Surgical Outcomes Research Centre (SOuRCe), The University of Sydney, NSW, Australia

Correspondence
Dr Glenn Salkeld
Surgical Outcomes Research Centre
E9W Royal Prince Alfred Hospital
Missenden Road
Camperdown, NSW 2050, Australia
E-mail: glenns@health.usyd.edu.au

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Keywords: colorectal cancer treatment, decision-making, surgeon, trust

Abstract

Objectives To determine which aspects of the treatment decision process, therapy and outcomes are most important to patients with colorectal cancer (CRC).

Design Cross-sectional survey.

Participants A total of 102 men and 73 women who had completed primary treatment for CRC in two teaching hospitals in Central Sydney, Australia.

Main outcomes measures Patient's rating of the importance of the decision-making aspects and outcomes of treatment for CRC.

Results Trust in their surgeon and confidence of specialty training are of paramount importance to CRC patients. Patients also have a strong desire to get on with treatment quickly and rate the risk of disease recurrence and quality of life as being very important in their treatment decisions. Gender, age and whether the patient had undergone adjuvant radiotherapy were all significant predictors of preferred mode of treatment decision-making. Fifty-eight per cent of women preferred a shared decision-making role compared with 36% of men, whilst older patients and those who had undergone adjuvant radiotherapy were significantly more likely to prefer that their surgeon decide upon treatment when compared with younger patients and respondents who have not had radiotherapy.

Conclusions Regardless of whether a patient prefers an active or more passive role in decision-making, having a surgeon explain treatment options in a clear, unhurried and open manner is vital to how patients feel about their treatment. Whilst acknowledging that individual patients will have different needs for information and preferences for treatment, there are several factors amongst many in the process of decision-making which are considered very important by patients with CRC. A surgeon who adopts a consultation style that is open and informative, that offers patients the chance to participate in the process of decision-making and clearly explain treatment options and outcomes will engender trust with their patient.

Introduction

Trust between a patient and their doctor is central to the care they receive. This relationship of trust is forged in the clinical encounter where crucial decisions about treatment are made and which will ultimately influence the long-term well-being of patients.[1] There are many factors that may influence, or impinge upon, the relationship between a patient and their doctor. Perhaps none more so than the practice of evidence-based medicine, multidisciplinary care and patient involvement in making treatment choices. Evidence-based surgery and patient involvement in deciding between particular treatment options in cancer surgery often require balancing quality of life outcomes with the chance of disease recurrence and survival outcomes. The multidisciplinary nature of cancer treatment often involves differing combinations of surgery, chemotherapy and radiotherapy for different stages of disease and this can make patient decision conflict a potential problem.[2] This conflict occurs repetitively in such common cancers as prostate, breast and rectal.[2] Together, these factors are driving a shift from the traditional model of care based on medical beneficence to the one more based on individual patient autonomy. This shift has been described as a move towards 'evidence-based patient choice' (EBPC).[3] EBPC is relatively new and, as Sheldon points out, there are difficulties in conceptualizing and implementing it.[4] But essentially EBPC is a concept that captures patients' desire for evidence-based information on treatment outcomes and the centrality of individual patient choices and values in medical decision-making. The central component of EBPC is a respect for the autonomy of patients to choose the role they would prefer in decision-making and an entitlement to receiving care that is based on evidence of what is known to be effective and safe.[5] That respect must come from their health-care providers. If the components of a good clinical encounter are in place, the outcomes for patients are generally more positive.[1] But as Dieppe argues, 'much work needs to be done to explore which components of the clinical encounter are of utmost importance'.[1,6] Henman *et al.*,[6] in a qualitative study on lay constructions of decision-making in cancer found that 'personal' factors were important to women with breast cancer in their decision-making. These included the feeling that the doctor cared for, understood and respected them; that they could trust and have confidence in their doctor; that the doctor would give them enough time, that they would be listened to; and that the doctor would be open and honest. If these factors were felt to be present, many women were happy to accept the doctor's recommendation, confident that they would receive optimum treatment. Yet other women felt there was no decision to be made, they just wanted to get on with their treatment.

In studies on patient preferences for colorectal cancer (CRC), most have focused exclusively on outcomes.[7] Whilst the outcomes of treatment, such as survival, side-effects and quality of life are very important to patients, the process of decision-making and their relationship with the specialist is also important as to how they feel about those outcomes in the long-term.[8–10]

In seeking the views of patients on treatment decisions for CRC, this study explores the relative importance that patients attach to the relationship with their surgeon, their involvement in decision-making and aspects of their treatment and outcomes.

Methods

The study was conducted in two stages. The first stage consisted of an interview-based qualitative study with 13 CRC patients. The interviews were used to address the relatively unexplored area of patients' own constructions and explanations of how they made decisions about treatment for CRC (paper in preparation). The main themes to emerge from the qualitative data were: the role of the surgeon, the decision-making process, patient support, the type of treatment and the outcomes of treatment. In the second stage, the results of the qualitative research were used to construct a self-administered questionnaire in which patients were asked to rate the importance of aspects of the treatment decision process and outcomes.

Sampling and recruitment

Participants were recruited from five colorectal surgeons who operate at two major teaching hospitals in Sydney, Australia. Eligible patients had a diagnosis of cancer of the colon or rectum, were a minimum of 6 months and maximum of 2 years post-resection, had completed any adjuvant therapy and were not undergoing any treatment or palliation, had no recurrence of disease and were English speaking. The sampling frame was based on a CRC database at each of the two hospitals. All eligible patients were contacted by telephone to explain the purpose of the study and obtain their consent to receive a questionnaire, with a covering letter from their surgeon. Mail details were confirmed for those consenting to participate. Follow-up strategies were instituted for non-participants.[11]

Measures

Patients' views on the treatment decision process, treatment and outcomes

Patients' views on the importance of aspects of the treatment decision process and outcomes were assessed by 38 questions that covered the range of issues identified in the qualitative research. Participants were asked to complete a self-administered questionnaire which was constructed in three parts. The first section asked patients whether or not a family member or friend had had CRC and, if so, their relationship to that person. The second section consisted of 22 Likert scale questions in which participants were asked to rate the importance of aspects of the decision-making process (1 = very important to 5 = not important at all). The third section consisted of 17 Likert scale questions in which participants were asked to rate the importance of aspects of the outcomes of treatment. Participants were also asked to select one of the five responses to a question assessing preferences for involvement in decision-making, adapted from a study by Degner *et al.*[12]

Demographics

Demographic details on the patient's age, gender, highest educational qualification achieved, occupation, marital status, years living in neighbourhood, stage of cancer, adjuvant therapy received, family member or friend with CRC, were requested from participants.

Statistical analysis

Descriptive analysis was conducted on all responses using the Statistical Package for Social Sciences (SPSS).[13] Likert responses were dichotomized into 'important' (very important + important) or 'neutral/unimportant' (neither important nor unimportant + not important at all + not so important) in order to conduct tests of association between sociodemographic variables and response variables. These tests were carried out using the Pearson χ^2 statistic. A higher level of statistical significance, $P < 0.01$, was set because of the multiple number of tests carried out.

Principal component analysis was conducted on the continuous data responses to 22 Likert questions on the treatment decision process and separately on responses to 17 Likert questions on the outcomes of treatment for 175 CRC patients. The purpose of this analysis is to identify a smaller number of components of the treatment decision process and outcomes of treatment based on the responses to the 39 individual questions. As interpretation of the components is in terms of the original variables, we used component correlations, or loadings, >0.5 to indicate those variables with which a component is correlated. This, in turn, provides a guide to the interpretation of that component. Both the eigenvalue greater than one criterion and the screen test were used to determine the number of components extracted, because the simple eigenvalue greater than one rule can sometimes lead to over-factoring.[14,15] The components were rotated to an orthogonal, Varimax simple structure solution.

A forward stepwise logistic regression was conducted with the preferred decision-making response as the dependent variable, dichotomized into 'surgeon decides' (surgeon alone decides + surgeon decide after taking my opinion into account) and 'shared decision-making' (all remaining categories) and independent variables including age, sex, employment status and adjuvant therapy.

Results

A total of 220 patients were eligible for inclusion in the study of whom 207 (94%) agreed to participate in the study and 175 questionnaires were returned (80% response rate). Demographic and clinical characteristics of participants, by gender, are presented in Table 1. Treatment differences between men and women reflect the age distribution and the slightly higher number of rectal cancers amongst the male participants.

Importance of aspects of the treatment decision process

The importance of each of the 22 aspects of the treatment decision process is summarized in Table 2, with the responses grouped according to the results of the principal component analysis. From this analysis, five factors were identified on the treatment decision process. The five factors were identified as trust in surgeon (F1), emotional support (F2), health services and referral (F3), information and communication (F4) and clinical care (F5). Factor 1, trust, accounts for 14.8% of the total variation in the 22 variables. Trust is based on the patient's perception of the surgeon's technical competency, the surgeon's openness, ability to talk to the patient in plain language and to listen to what the patient has to say. Factor 2, emotional support, accounts for 11.7% of the total variation and is based on whether a patient feels supported in their decision-making by their GP, family, friends and other CRC patients. Factor 3, health services and referral accounts for 9.25% of the total variation. This component reflects a patient's desire to get treatment as quickly as possible where the surgeon considers their needs and keeps their GP informed of their treatment. Factor 4, information and communication, accounts for 9.25% of the total variation. It represents the surgeon's ability to explain all the treatment options, to provide written information on treatment and the patient's ability to get information from other sources (including a second opinion if desired). Factor 5, clinical care, accounts for 8% of the total variation. This component reflects the importance of the surgeon's specialization in CRC and the availability of a CRC patient support group. Together, the five components account for 53% of the variability in responses.

Relationship between the importance of the treatment decision process and specific patient characteristics

Three characteristics of participants, highest level of education obtained, employment status and marital status were associated with the importance that patients attached to the treatment decision process. Thirty-five per cent of participants who had completed a trade or higher education qualification thought it was important to let the family have a say about their treatment compared with 56% of participants who had not completed this level of education ($\chi^2 = 1\ 4.1$, 4 d.f., $P = 0.007$). Nineteen per cent of participants who were employed, a student or had retired from work, thought it was important to listen to what friends had to say about their treatment compared with 48% of

Table 1 Demographic and clinical characteristics of the respondents, by gender

	Men (n = 102) n (%)	Women n = 73 n (%)	Total n = 175 n (%)
Age group			
≤50 years	9 (9)	9 (13)	18 (11)
51–64 years	29 (29)	20 (28)	49 (29)
65–74 years	33 (33)	17 (24)	50 (29)
75 years+	29 (29)	26 (36)	55 (32)
Highest level of education			
Did not complete secondary school	39 (39)	29 (40)	68 (40)
Completed secondary school	16 (16)	22 (31)	38 (22)
Trade or technical qualification	26 (26)	10 (14)	36 (21)
University or college	19 (19)	10 (14)	29 (17)
Employment status			
Employed or student	23 (23)	14 (19)	37 (22)
Not employed	77 (77)	58 (81)	135 (78)
Marital status			
Married	81 (83)	36 (49)	117 (68)
Other	17 (17)	37 (51)	54 (32)
Years living in neighbourhood			
< 5 years	15 (15)	12 (17)	27 (16)
Between 5 and 10 years	10 (10)	14 (20)	24 (14)
Between 10 and 20 years	13 (13)	8 (11)	21 (12)
More than 20 years	63 (62)	37 (52)	100 (58)
Treatment – chemotherapy			
Yes	28 (28)	11 (16)	39 (23)
No	71 (72)	60 (85)	131 (77)
Radiotherapy			
Yes	15 (15)	4 (6)	19 (11)
No	84 (85)	68 (94)	152 (89)
A family member has ever had bowel cancer			
Yes	28 (28)	28 (39)	56 (33)
No	57 (57)	38 (53)	95 (55)
Do not know	15 (15)	6 (8)	72 (172)
A friend has ever had bowel cancer			
Yes	45 (45)	19 (26)	64 (37)
No	46 (46)	40 (55)	86 (50)
Do not know	9 (9)	13 (18)	22 (13)
Stage of cancer at diagnosis			
Dukes stage A	52 (54)	46 (66)	98 (59)
Dukes stage B	26 (27)	15 (21)	41 (25)
Dukes stage C	17 (18)	9 (13)	26 (16)

Where data are missing, columns do not add up to *n*.

participants who were employed in home duties, unemployed or unable to work ($\chi^2 = 8.9$, 1 d.f., $P = 0.003$).

Importance of aspects of the outcomes of treatment

The importance of each of the 17 aspects of treatment and outcomes is summarized in Table 3, with the responses grouped according to the results of a second principal component analysis. In this analysis, four factors were identified on the outcomes of treatment, accounting for 63% of the variance. The four factors were identified as getting on with life (F1), adjuvant therapy and side-effects (F2), type of surgical procedure (F3), and disease recurrence and quality of life (F4; 11.3% of variance). Factor 1, getting on with life, accounts for 19.7% of the total variation in the

Table 2 Respondents' rating of the importance of aspects when choosing treatment for colorectal cancer

Attribute statement (n = 175)	Total 'very important' or 'important' (%)	Total 'neither important nor unimportant' + 'not important'
Based on your experience, what do you think are the important aspects when choosing any treatment for colorectal cancer?		
F1. Surgeon – trust		
Have surgeon who is up-to-date with treatment options	100	–
Have the surgeon explain the treatment in a straight-forward manner	99	1
Have the surgeon be open about the patient's condition and prognosis	99	1
Have the surgeon give plenty of time and not hurry the consultation	98	1
Have a lot of support from the family	96	2
Have the surgeon listen to what the patient has to say	94	3
F2. Emotional support		
Have my GP help with treatment decisions	56	21
Hear about the experience of someone who has had colorectal cancer	55	20
Let the family have a say about treatment	42	24
Listen to what friends have to say about the treatment	22	24
F3. Health Services & referral		
Have surgery as soon as possible	98	2
Surgeon considers patient's needs	98	2
Medical specialists keeping GP informed	90	8
Be referred to a surgeon by someone the patient trusts	89	9
Referred to a surgeon who operates at a teaching hospital	68	21
F4. Information and communication		
All treatment options are explained	94	4
Receive written information on the treatment options	78	7
Get as much information from as many sources as possible	66	18
Take time to think about treatment decisions before commencing trt	62	15
Get a second opinion	46	30
F5. Clinical care		
Surgeon only treatments colorectal cancer disorders	95	3
Have a colorectal cancer patient support group available	63	2

17 variables. Factor 2, adjuvant therapy and side-effects accounts for 16.9% of variance. This component is based on the desire to minimize pain and regret associated with treatment, a general desire to avoid adjuvant therapy if possible and to minimize the side-effects of treatment. Factor 3, type of surgical procedure, accounts for 15.4% of variance and is based on a patient's desire to avoid a big operation and/or the need for a colostomy bag. Factor 4, disease recurrence and quality of life, accounts for 11.3% of variance. This component reflects a patient's desire to minimize the chance of a disease recurrence and to return to a normal quality of life. Together, the four components account for 63% of the variability in responses.

Relationship between the importance of the treatment decision process and specific patient characteristics

Three characteristics of participants, a family member with CRC, whether the patient had undergone adjuvant therapy and highest level of education obtained were associated with the importance that patients attached to the outcomes of treatment. These results are summarized in Table 4.

Table 3 Respondents' rating of the importance of aspects of the outcomes of treatment

Attribute statement ($n = 175$)	Total 'very important' or 'important' (%)	Total 'neither important nor unimportant' + 'not important'
It is important to choose a treatment which would:		
F1. Getting on with life		
Get everything done as quickly as possible to get on with life	78	11
Minimize any disruption to the patient's lifestyle while having treatment	65	14
Keep the family happy	51	19
Get the patient back to work as quickly as possible	49	22
Minimize the cost of having treatment	48	21
Ensure that business/work was minimally affected	36	24
F2. Adjuvant therapy and side effects of treatment		
Leave no feelings of regret	88	5
Minimize pain during treatment	83	8
Avoid the unpleasant side-effects of the treatment, such as nausea, diarrhoea and dry mouth	70	14
Avoid having chemotherapy	57	20
Avoid having radiotherapy	57	20
F3. Type of surgical procedure		
Avoid having a permanent colostomy bag	82	8
Avoid having a temporary colostomy bag	58	16
Avoid a big operation	55	22
F4. Recurrence of CRC and quality of life		
Reduce the risk of the colorectal cancer coming back	100	–
Result in a normal quality of life after the treatment has finished	100	–
Avoid any long-term pain as a result of treatment	97	1

Preferred mode of decision-making

Participants' preferred mode of decision-making is summarized in Table 5. The results of the logistic regression analysis showed that gender, age and whether the patient had had radiotherapy were significantly associated with their preferred decision-making role (Table 6). Women are 2.6 times more likely than men to choose a shared decision role whilst patients who have undergone adjuvant radiotherapy are 80% less likely to prefer a shared decision role with their surgeon compared with those who have not had radiotherapy. Age is negatively related to preferred decision-making role, which means older patients are more likely to prefer the surgeon to decide their treatment. A patients' employment status, their surgeon, stage of cancer and level of education were not statistically significant predictors of decision-making role.

Discussion

From the patient's point of view, establishing trust in their surgeon was very important and was crucial in accepting that the right treatment decisions were being made. Trust was built on confidence in the expertise of their surgeon and a belief that their doctor was genuinely concerned about them. Henman *et al.*,[6] in a qualitative study of lay constructions of decision-making found that genuine concern was seen in giving adequate time for a consultation, being listened to, having questions answered and the doctor having a caring and empathetic attitude. We found that all these factors associated with the process of the consultation were very important for the participants in this study. Confidence was also based on the patients' perception that their surgeon had specialist knowledge and training in CRC, was up-to-date with treatment options and was prepared to listen to what the patient had to

Table 4 Relationship between the importance of the treatment decision process and specific patient characteristics

Patient characteristic	Variable (%) (rating variable as 'very important' or 'important')	χ^2	*P*-value
Family member has colorectal cancer			
Avoiding side-effects of treatment			
Yes	80	18.5 (2 d.f.)	<0
No	67		
Do not know	33		
Patient has had chemotherapy			
Avoiding chemotherapy			
Yes	25	20.86 (1 d.f.)	<0
No	67		
Patient has had chemotherapy			
Avoiding radiotherapy			
Yes	34	10.8 (1 d.f.)	0.001
No	65		
Patient has had radiotherapy			
Have trt quickly and get on with life			
Yes	56	6.5 (1 d.f.)	0.01
No	82		
Highest level of education			
Avoiding side-effects of treatment			
Did not complete secondary	85	14.7 (3 d.f.)	0.005
Completed secondary school	62		
Trade or technical qualification	63		
University or college	53		
Highest level of education			
Avoiding a very big operation			
Did not complete secondary	73	15.0 (3 d.f.)	0.005
Completed secondary school	44		
Trade or technical qualification	40		
University or college	43		
Highest level of education			
Minimize pain during treatment			
Did not complete secondary	94	16.9 (3 d.f.)	0.002
Completed secondary school	84		
Trade or technical qualification	83		
University or college	60		

say. For some, confidence was enhanced by more active participation in decision-making with their surgeon. Fallowfield and colleagues studied 269 women with early stage breast cancer from the time of diagnosis for 3 years.[16,17] The authors concluded that the consultation style of surgeons is more important for psychological well-being than being allowed choice of treatments. That is, being a participant in decision-making is more critical for patient well-being than actually determining the direction of their care. What is it about decision-making that is important to patients?

A recent qualitative study on decision-making in cancer found that even when patients report a desire for collaborative decision-making, they rely heavily on their doctor's opinion and seek rather to *understand* the rationale behind the doctor's recommendation than to make the decision themselves.[6] Having a surgeon explain treatment options in a clear, unhurried and open manner was important or very important to

Table 5 Respondents' preferred mode of treatment decision-making, by gender

	Men (n = 102) n (%)	Women (n = 73) n (%)	Total (n = 175) n (%)
Decision-making role			
I decide	2 (2)	1 (1)	3 (2)
Myself but consider surgeon's opinion	10 (10)	14 (20)	24 (14)
Surgeon and I share	24 (24)	26 (37)	50 (29)
My surgeon decides but considers my opinion	33 (33)	16 (23)	49 (29)
My surgeon decides	32 (32)	13 (19)	45 (26)

Where data are missing, columns do not add up to n.

Table 6 Logistic regression model of factors associated with preferred decision-making role*

Category	β	SE	Odds ratio (95% CI)
Gender			
Male			1†
Female	0.961	0.338	2.62 (1.35–5.1)
Whether the patient had adjuvant radiotherapy			
No			1†
Yes	−1.642	0.691	0.194 (0.050–0.75)
Age (continuous variable)	−0.40	0.014	0.961 (0.934–0.989)

*Outcome variable 0 = surgeon decides; 1 = shared decision-making role.
†Reference category.

98% of our study participants. At the same time, patients wanted the surgery as quickly as possible and less than half wanted a second opinion. This is consistent with qualitative studies in which patients say that they are afraid to take up too much of their specialist's time. Only 56% of respondents wanted their GP to help with the treatment decision.

Seeking to understand treatment is important for both men and women, regardless of whether they preferred an active or more passive role in decision-making. Yet, women do prefer to take a more active role in the decision-making process. A recent study on women's decision-making preferences for breast cancer screening and treatment found that 91% preferred to share decision-making equally with their doctor or to take a more active role.[18] This is consistent with other studies on patient preferences for breast cancer treatment. Men appear to be more willing to allow some degree of paternalism in decision-making (with over 60% of men in our sample wanting the surgeon to decide) as do older patients. Both gender and age were significantly associated with a preference for the surgeon to decide treatment. Leydon *et al.*[19] in their study of cancer patient's information needs found that older patients and men are more likely to adopt a 'non-participatory' role in the management of their illness. Men maintained a sense of hope (for survival) through silence and, more generally, through 'strength of silence and this influenced their desire for more information and avoidance of new information'.[19]

Making treatment choices that would leave no feelings of regret was rated as important or very important by 88% of participants. In a study by Clark *et al.*[20] on treatment decisions for men with metastatic prostate cancer, regret was strongly associated with poor quality of life and was negatively associated with satisfaction with both treatment choice and decision-making role. The more regret felt by a patient the less satisfied they were with the outcome of treatment. Other studies have found a clear association between decision-making role and psychological well-being. Gattelari *et al.*[7] in a study on sharing decisions in cancer, followed 233 patients before and after their treatment consultation and measured the impact of shared decision-making and the achievement of preferred role on patient anxiety, recall of information and satisfaction. The authors found that failure to achieve preferred decision-making roles adversely affected patient emotional well-being, particularly anxiety levels. Specifically, 'less involvement than preferred appears more detrimental than involving patients to a greater degree than preferred'. This finding suggests that it is better to provide the opportunity for including the patient in decision-making during the consultation and to respect their input even where a patient expects the surgeon to make the final decision.

Within the sampling frame, there were 14 patients who were undergoing treatment or palliation and four patients who were non-English speaking. In accordance with the eligibility criteria, these patients were not approached to participate in the study. The views of patients undergoing treatment or palliation may have been different from the eligible group by virtue of their circumstances. Opinions may be influenced by the immediacy of the need to undergo treatment or palliation and the desire to get back to health. More generally, a key question is whether patient opinions about decision-making are likely to change over time.

We knew from the qualitative research in stage 1 that survival was the highest priority for most patients. A typical comment on surviving their cancer was

> …your priorities, what you were weighing up? …Stay alive, that is all I thought about …you have got to survive.

This is consistent with the findings of Little *et al.*[21] where CRC patients expressed the view that they wanted the best chance of survival (this was assumed knowledge) and Beaver *et al.*[8] where CRC patients ranked cure as the most important factor to them. Beyond the immediate desire for survival lay concerns about their long-term quality of life and the chance of the CRC coming back. Both these factors were rated as important by all the participants in this study. However, the means by which they achieved these outcomes also mattered. There was a very clear sociodemographic gradient in the perception of patients on the impact of treatment on their health. Participants who had not completed primary or high school thought it was more important to avoid having a big operation, to avoid the side-effects of treatment and to minimize pain during treatment compared with more highly educated patients. The results do not provide any insight as to why this might be the case. It is possible that the provision of more information on managing pain and side-effects would change the individuals' perception of the importance of these factors.

It is not surprising that the views of patients who had undergone adjuvant therapy were systematically different from those who had not. In two separate studies, Henman *et al.*[6] and Charles *et al.*[22] found that by accepting adjuvant treatment, women could reassure themselves that they had done everything possible to maximize the chances of avoiding disease recurrence. Hence women felt that avoiding adjuvant therapy was simply out of the question. Once having survived a difficult experience, most people become more strongly convinced of the correctness of their decision to undergo it because the alternative (that adjuvant therapy was all for nothing) is too distressing. Nonetheless, 25% of patients who had chemotherapy thought it was important to avoid having adjuvant therapy, suggesting an element of regret. Further research is needed to determine which factors (such as quality of life) have the most influence on a decision to have adjuvant therapy and on experiencing regret afterwards.

The principal component analysis reduced the 22 items on the decision-making process down to five components and the 17 items on the outcomes of treatment down to four components. We suggest that these nine components are qualitatively generalizable to other CRC surgical settings. For the sake of wider generalizability, other researchers wishing to explore decision-making in CRC might use these nine components as the basis of further study in this area.

Conclusion

Whilst acknowledging that individual patients will have different needs for information and preferences for treatment, there are several factors amongst many in the process of decision-making which are considered very important by patients with CRC. A surgeon who adopts a consultation style that is open and informative, that offers patients the chance to participate in the process of decision-making and clearly explain treatment options and outcomes will engender trust with their patient.

Conflict of interest

None declared.

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