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Colorectal cancer patients' attitudes towards involvement in decision making

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Abstract

Objectives To design and administer an attitude rating scale, exploring colorectal cancer patients' views of involvement in decision making. To examine the impact of socio-demographic and/or treatment-related factors on decision making. To conduct principal components analysis to determine if the scale could be simplified into a number of factors for future clinical utility.

Methods An attitude rating scale was constructed based on previous qualitative work and administered to colorectal cancer patients using a cross-sectional survey approach.

Results 375 questionnaires were returned (81.7% response). For patients it was important to be informed and involved in the decision-making process. Information was not always used to make decisions as patients placed their trust in medical expertise. Women had more positive opinions on decision making and were more likely to want to make decisions. Written information was understood to a greater degree than verbal information. The scale could be simplified to a number of factors, indicating clinical utility.

Conclusion Few studies have explored the attitudes of colorectal cancer patients towards involvement in decision making. This study presents new insights into how patients view the concept of participation; important when considering current policy imperatives in the UK of involving service users in all aspects of care and treatment.

Background

Clinical decision making in the cancer field is becoming increasingly complex with a host of therapeutic regimes, a variety of risk–benefit profiles and uncertain outcomes. There are important considerations and implications for patients who want to take a proactive role in decision making, balancing survival and quality of life benefits and costs. In the UK the National Health Service (NHS) Cancer Plan states that patients should have 'choice, voice and control' over their care and treatment.[1] However, evidence is conflicting on whether patients want to make treatment and care choices or whether they are encouraged to do so by health professionals. For colorectal cancer (CRC) patients, a range of treatment and care modalities exist. Hence there should be many opportunities for patients to participate in the decision-making process. However, there is evidence to suggest that CRC patients may not wish to be actively involved in making decisions about their treatment and may prefer to defer decision-making responsibility to doctors.[2] While it would not be deemed ethical to insist that patients make decisions if they did not wish to do so, it could be argued that health professionals have a responsibility to establish patient preferences for participation and offer choices to those who do want to make decisions. While there is some evidence that certain socio-demographic and disease-related factors, such as age, level of education, social class, gender and severity of disease, are predictors of preferences,[3–5] the evidence in this area is by no means conclusive.

Despite recommendations that CRC patients should be given clear information about their disease and treatment options,[6] and increasing interest in the concept of shared decision making, there is still relatively little evidence that these recommendations translate into practice, given the inherent complexities of restructuring the traditional paternalistic relationship between health providers and patients. In addition, there is a dearth of research considering the attitudes and beliefs of health consumers in relation to active participation in treatment decisions and the subsequent impact on health and quality of life outcomes.[7]

Lack of sufficient and timely information remains a common complaint among oncology patients in the UK and communication difficulties are well-documented but changing attitudes and clinical practice in relation to patients' active participation in health care is challenging.[8] There is a distinction between patients wanting information and assuming the responsibility of active decision makers, and the process of systematically assessing individual preference in relation to involvement remains crucial.[4,9,10]

This study focuses on the process of patient involvement in decision making and the relationships between providers and consumers of health care as perceived by patients with CRC. The study was conducted in three stages. Stage 1 investigated the decision-making preferences of 41 people with CRC using in-depth qualitative interviews.[11] Stage 2 aimed at understanding the complexities of offering patients choices from a health professional perspective, using in-depth interviews with 35 medical, nursing and allied health professionals.[12] A number of pertinent themes emerged from this qualitative work. For patients, participation in the decision-making process was synonymous to being informed and involved. Patients did not necessarily want to make decisions but they did want to know what was happening to them. Patients placed their trust in medical expertise and indicated their own lack of medical knowledge. Patients perceived that there were few choices to be made about surgical treatment but reported that more choices were available with regard to adjuvant therapy (radiotherapy, chemotherapy). Health professionals could often make assumptions about patients' preferred levels of involvement in decision making based on demographic factors such as age. Findings from stages 1 and 2 were informative but involved small samples. This paper describes stage 3 of the study where findings from qualitative work were used to develop an attitude rating scale that could be administered to a larger sample of patients treated for colorectal cancer. In this way, findings from qualitative work in this under-researched group could be confirmed, providing valuable information on the challenging and complex area of patient involvement in healthcare decision making.

Aims

The aims of this study were: (i) to design and administer an attitude rating scale that would build on qualitative work and explore CRC patients' attitudes towards their involvement in decision making; (ii) to examine if socio-demographic or treatment-related factors impacted on patient attitudes towards decision-making involvement; (iii) to carry out exploratory factor analysis to determine if the attitude rating scale could be simplified into a number of factors that could have future clinical utility.

Methods

Development and piloting of attitude scale

Attitude statements were initially constructed independently by the research team, based on themes that had emerged in stage 1. In subsequent meetings, statements were pooled. This 'item pool' formed the basis of the attitude scale.[13] In the early stages of development, there was much duplication of statements; statements considered repetitive were removed or merged. Once agreement was reached, statements were randomly ordered and formed the first section of a questionnaire. Some statements were written in negative format (e.g. 'I do not understand the written information I am given') in an attempt to ensure that participants would read questions carefully prior to responding.

Pilot testing was conducted with 20 CRC patients; statements were evaluated for readability, whether they had meaning for patients, repetition or redundancy. Instructions for completion of the measure were also evaluated. Some negatively worded questions were considered overly complex and were amended. Certain expressions were not readily understood. For example, 'mental health' was perceived as more meaningful than 'psychological care' or 'mental state'. Following pilot testing, the questionnaire was considered to have reasonable content validity; it was understandable, meaningful and took approximately 10–15 min to complete. A total of 26 statements were included in the final version of the measure.

Responses to statements related to strength of agreement, on a five-point scale ranging from 'strongly agree' to 'strongly disagree'. For six statements, a 'not applicable' option was necessary; e.g. if the question related to chemotherapy and the patient had not undergone chemotherapy. The completed questionnaire comprised three main sections: attitude rating scale (26 statements); demographic/treatment details; and an open question where patients could reflect on responses and provide general comments if they wished to do so.

Setting and participants

Participants were recruited from three NHS Trusts in the north-west of England, to allow a representative view and to ensure sample size targets were met, including two Cancer Centres (site 1, site 2) and a large District General Hospital (site 3). Inclusion criteria were adults with a first-time diagnosis of CRC who had completed treatment, were aware of their diagnosis and considered physically and psychologically able by clinical colleagues to be approached for consent. Patients were at different time points from diagnosis at recruitment. Data collection took place in oncology outpatient clinics, surgical outpatient clinics and a day case chemotherapy unit. Patients who met the inclusion criteria were asked to complete a questionnaire at their own convenience and return by post (pre-paid) to the research team. Local Research Ethics Committee approval to conduct the study was received in addition to R&D approval from the relevant Trusts.

Sample size

Exploratory factor analysis, an exploratory statistical technique used to analyse correlations between the attitude statements, was proposed to confirm commonalities between statements. The smaller the sample size the larger the standard error of the correlations and the more likely that error will be contained in the analysis. Samples of less than 100 can produce misleading results[14] and it has been suggested that about 150 cases are required for a 'good solution'[15] or a minimum of 10 participants per item in a questionnaire.[16] Therefore, we aimed for a sample size of approximately 260 (26 × 10). However, as response rates to postal surveys are typically low (30–35%), it was anticipated that approximately 460 questionnaires would need to be distributed.

Analysis

Descriptive analysis was carried out on all responses to the attitude statements using SPSS® for Windows (v13). Exploratory factor analysis based on correlations between variables was used to find common factors underlying the statements in the attitude rating scale. In a main analysis, participants were excluded from factor analysis if they had one or more missing responses over the variables under consideration (listwise deletion). In a secondary analysis, the correlation between each pair of variables was estimated using all participants with valid responses on that pair (pairwise deletion) to assess the impact of omitting participants with missing values. The Kaiser–Meier–Olkin measure of sampling adequacy was estimated over all variables combined and for individual variables to assess the viability of factor analysis.[15] To avoid biasing the data used by treatment experienced and to help maximize the number of participants with no missing values, factor analysis was initially performed using the 20 statements that were relevant to all participants (excluding the 'not applicable' items).

Principal components analysis was used to indicate the number of factors likely to be present, based on the number of components with eigenvalues >1.0. Factors were extracted using principal axis factoring in the main analysis, and maximum likelihood factoring in a secondary analysis (the Likert scale variables were not normally distributed) for comparison. Factors were then rotated using orthogonal Varimax rotation and oblique Oblimin rotation, and the rotated factors were compared to find a consistent and meaningful solution.[15]

Scores on the rotated factors were estimated for each patient with complete data on the variables used for factor analysis. Relationships between the factor scores and individual personal and clinical variables were assessed using t-tests to compare mean scores for groups defined by variables with two categories (e.g. gender), one-way analysis of variance to compare mean scores for groups defined by variables with more than two categories (e.g. marital status), and Kendall's tau correlation to measure concordance between factor score and potentially skewed interval variables (e.g. time from diagnosis). Given the exploratory and tentative nature of the extracted factors, a multivariate analysis of the explanatory variables was not pursued.

Results

A total of 459 questionnaires were distributed and 375 were returned (81.7% response rate), in excess of target sample size. A typical respondent was male, married, with no formal qualifications and employed in a skilled occupation (Table 1). The majority of patients responding to a question on ethnic group were White British (91%, 316/349).

The sample for exploratory factor analysis was adequate (overall Kaiser–Meier–Olkin coefficient = 0.75). Analysis initially related to the 20 attitude statements that were applicable to all patients (Table 2). The statement 'I like to discuss my treatment with my GP' had very low commonalities before and after factor extraction for both principal axis factoring (0.18 and 0.15 respectively) and maximum likelihood factoring (0.18 and 0.12 respectively). This variable also had poor loadings on extracted factors. The statement appeared to have little in common with the other 19, and was dropped from subsequent analysis.

Principal components analysis showed six components with eigenvalues >1, accounting for 61% of the total variance. The pattern of factor loadings was generally similar for different combinations of factoring method (principal axis and maximum likelihood) and rotation (Varimax and Oblimin). None of the 15 correlations between Oblimin-rotated factors was greater than 0.32 for principal axis factoring; the two highest correlations for maximum likelihood factoring were 0.34 and −0.33. This suggested that a simpler orthogonal rotation would be sufficient.[15] The results below are for principal axis factoring with Varimax rotation, where the rotated six-factor solution explained 45% of the total variance.

Table 1 Characteristics of the study sample (n = 375)

Variable	Total (n = 375)
Age	
Mean (SD)	65.4 (11.2)
Median (IQR)	67.0 (58.0 to 73.0)
Gender	
Male	219 (58.4%)
Female	156 (41.6%)
Marital status[1]	
Married/cohabiting	249 (67.5%)
Widowed	34 (9.2%)
Divorced/separated	63 (17.1%)
Never married	23 (6.2%)
Educational qualifications	
Degree/diploma	58 (15.5%)
Professional/vocational/other	56 (14.9%)
Secondary school (GCSE, O, A level)	57 (15.2%)
None	204 (54.4%)
Social class	
Professional/managerial and technical	89 (23.7%)
Skilled	152 (40.5%)
Partly skilled/unskilled	30 (8.0%)
Not applicable/not known	104 (27.7%)
Time from diagnosis (months)	
Mean (SD)	24.0 (24.0)
Median (IQR)	18.0 (7.0 to 31.0)
Surgery	
Yes	329 (87.7%)
No	46 (12.3%)
Radiotherapy	
Yes	114 (30.4%)
No	261 (69.6%)
Chemotherapy	
Yes	255 (68.0%)
No	120 (32.0%)

[1] Only 369 patients gave valid responses to the question on marital status.

The rotated factor with the highest sum of squared loadings, factor 1, was a 'decision-making' factor, accounting for 13.1% of the total variance. While 94.7% reported that they wanted to know what was happening to them and be involved in treatment decisions, only 57.1% actually wanted to decide what treatment to have. However, 86.2% wanted to share the decision-making process with their doctor.

Factor 2 was a 'communication' factor, accounting for 9.1% of the variance; 76.8% reported that they disagreed with the statement 'I do not understand the written information I am given' indicating that written information was understandable and may be considered useful. However, there were missing data for this item (n = 22); some patients may not have received written information and were therefore unable to respond.

Factor 3 represented 'trust' in medical expertise, accounting for 7.3% of the variance. There were high levels of agreement with the two statements that comprised this factor; 95.2% of the patients agreed with the statement 'I trust the doctor to decide the best treatment for me' and 84.8% agreed that 'doctors have medical knowledge, so they should decide what treatment is best for me'.

Factor 4 appeared to contain items related to 'low information needs' or difficulties with access to information, accounting for 5.8% of the variance; 23.2% of the patients did not like to bother the doctor with questions about their treatment and 44.6% liked to get information a bit at a time. However, 83.5% of the patients agreed that they found talking to nurses helped to make sense of what the doctor had said.

Factor 5 had high loadings on the two statements related to making treatment choices and accounted for 5.5% of the total variance; 80.3% of the patients agreed that they had enough time to think about treatment choices. The negative rotation sum of squares loading for the item 'I was not given any choice about which treatment to have' (−0.49) reverses the sense of the statement with higher scores corresponding to more positive views on choices; 48% disagreed with this statement.

Factor 6 only had a high loading on a single statement, 'I find the hospital clinic too busy to discuss my treatment'; only 16.3% agreed with this statement. However, such a factor would be considered 'poorly defined'.[15]

When principal axis factoring with Varimax rotation was repeated using pairwise deletion to estimate the correlation matrix, results generally agreed with those for listwise deletion. Six items had a 'not applicable' option and had not been included in the principal components analysis. Responses to these statements are presented in

Table 2 Responses to attitude statements according to factor loading (n = 375)

Factor: description (rotation sum of squared loadings (RSSL); % of variation explained)	Rotated factor loading	Strongly agree ⁄ agree, *n* (%)	Neither agree nor disagree, *n* (%)	Disagree ⁄ strongly disagree, *n* (%)	Missing, *n* (%)
Factor 1: decision-making (RSSL = 2.49; 13.1% explained)					
I want to decide what treatment to have	0.74	214 (57.1)	60 (16.0)	86 (22.9)	15 (4.0)
If a doctor tells me everything I am more likely to want to make decisions	0.69	295 (78.6)	45 (12.0)	29 (7.7)	6 (1.6)
I expected to be asked whether I wanted to make choices about my treatment	0.62	248 (66.2)	50 (13.3)	61 (16.3)	16 (4.3)
I want to share decisions about my treatment with the doctor	0.59	323 (86.2)	26 (6.9)	17 (4.6)	9 (2.4)
I want to know what is happening to me and be involved in decisions about my treatment	0.48	355 (94.7)	15 (4.0)	5 (1.3)	0 (0.0)
When I am at home I want to make decisions about my physical care	0.47	315 (84.0)	39 (10.4)	15 (4.0)	6 (1.6)
I feel comfortable asking the doctor questions about my treatment	0.35	352 (93.9)	12 (3.2)	8 (2.2)	3 (0.8)
Factor 2: communication (RSSL = 1.73; 9.1% explained)					
I do not understand the written information I am given	0.85	31 (8.3)	34 (9.1)	288 (76.8)	22 (5.9)
I do not understand the words used by doctors about treatments	0.67	61 (16.3)	56 (14.9)	251 (67.0)	7 (1.9)
I have not been given all the treatment information I need	0.52	37 (9.9)	38 (10.1)	290 (77.4)	10 (2.7)
Factor 3: trust (RSSL = 1.38; 7.3% explained)					
Doctors have medical knowledge, so they should decide what treatment is best for me	0.72	318 (84.8)	21 (5.6)	28 (7.5)	8 (2.1)
I trust the doctor to decide the best treatment for me	0.67	357 (95.2)	12 (3.2)	5 (1.4)	1 (0.3)
Factor 4: low information needs (RSSL = 1.10; 5.8% explained)					
I do not like to bother the doctor with questions about different treatments	0.53	87 (23.2)	44 (11.7)	234 (62.4)	10 (2.7)
I like to get information a bit at a time	0.47	167 (44.6)	91 (24.3)	107 (28.5)	10 (2.7)
I do not want to be involved in decisions about my mental health	0.41	60 (16.0)	55 (14.7)	239 (63.7)	21 (5.6)
I find talking to the nurse helps me to make sense of what the doctor has said	0.32	313 (83.5)	43 (11.5)	12 (3.2)	7 (1.9)
Factor 5: treatment choice (RSSL = 1.04; 5.5% explained)					
I had enough time to think about treatment choices	0.66	301 (80.3)	43 (11.5)	16 (4.3)	15 (4.0)
I was not given any choice about which treatment to have	−0.49	138 (36.8)	40 (10.7)	180 (48.0)	17 (4.5)
Factor 6: time (RSSL = 0.74; 3.9% explained)					
I find the hospital clinic too busy to discuss my treatment	0.66	61 (16.3)	45 (12.0)	257 (68.5)	12 (3.2)
Non-loading item					
I like to discuss my treatment with my GP		241 (64.2)	76 (20.3)	45 (12.0)	13 (3.5)

Table 3 Responses to statements with 'not applicable' option

Attitude statement	Strongly agree ⁄ agree, *n* (valid %)	Neither agree nor disagree, *n* (valid %)	Disagree ⁄ strongly disagree, *n* (valid %)	Missing, *n* ⁄375 (%)	Not applicable, *n* ⁄375 (%)
I want to make decisions about surgery	220 (67.5)	42 (12.9)	64 (19.6)	5 (1.3)	44 (11.7)
There was no choice about surgery	204 (65.6)	27 (8.7)	80 (25.7)	9 (2.4)	55 (14.7)
I want to make decisions about chemotherapy	201 (62.6)	46 (14.3)	74 (23.1)	6 (1.6)	48 (12.8)
There was no choice about chemotherapy	126 (43.4)	23 (7.9)	141 (48.6)	10 (2.7)	75 (20.0)
I want to make decisions about radiotherapy	109 (54.5)	39 (19.5)	52 (26.0)	10 (2.7)	165 (44.0)
There was no choice about radiotherapy	90 (45.2)	35 (17.6)	74 (37.2)	10 (2.7)	166 (44.3)

Table 3; 65.5% of the patients reported that there was no choice about surgery compared with 45.2% for radiotherapy and 43.4% for chemotherapy. However, 67.5% of the patients indicated that they wanted to make decisions about surgery compared with 62.6% for chemotherapy and 54.5% for radiotherapy.

Relationships between individual variables and factor scores

A number of socio-demographic and clinical variables were examined to assess their impact on each of the six rotated factor scores. For factor 1 (decision making), only gender showed a statistically significant association ($t = -2.48$, d.f. = 307, $P = 0.01$). Female patients had a higher mean score than male patients, indicating more positive opinions on decision making. Female patients showed considerably more agreement than male patients with 'I want to decide what treatment to have'; 72.0% of female patients (108⁄150) agreed compared with 50.4% (106⁄210) of males (chi-squared test for trend: $\chi^2 = 16.35$, d.f. = 1, $P < 0.01$).

Factor 2 (communication) was significantly associated with social class ($F = 3.51$, d.f. = 3, 305, $P = 0.02$), months since diagnosis ($\tau = 0.09$, $P = 0.02$) whether the patient had chemotherapy (t = −2.27, d.f. = 307, $P = 0.02$) and age ($\tau = 0.08$, $P = 0.03$). Patients classified under professional, managerial or technical occupations had a better understanding of the information given. Patients who had undergone chemotherapy showed more understanding on average than those who had not. In general, patients showed better understanding of written information than verbal information from doctors: only 31 of 353 patients agreed with the statement 'I do not understand the written information I am given', while 61 of 368 agreed with the statement 'I do not understand the words used by doctors about treatments'. Older patients and those who had been diagnosed longer tended to show less understanding.

Factor 3 (trust) was significantly associated with study site ($F = 7.33$, d.f. = 2, 306, $P < 0.01$), educational qualifications ($F = 3.01$, d.f. = 3, 305, $P = 0.03$) and whether the patient had undergone radiotherapy ($t = 2.39$, d.f. = 307, $P = 0.02$). A greater degree of trust was apparent at site 1. Patients with lower levels of educational qualifications were more likely to indicate trust in the doctor. The statement 'Doctors have medical knowledge, so they should decide what treatment is best for me' showed the strongest association with educational qualifications. Those with lower levels of educational qualifications were more likely to agree with this statement. Patients who had undergone radiotherapy showed a greater degree of trust on average than those who had not.

Factor 4 (low information needs) was significantly associated with age ($\tau = 0.18$, $P < 0.01$), educational qualifications ($F = 4.99$, d.f. = 3, 305, $P < 0.01$), social class ($F = 9.84$, d.f. = 3, 305, $P < 0.01$), marital status ($F = 3.93$, d.f. = 3, 300, $P = 0.01$) and gender ($\tau = 0.18$, $P = < 0.01$). Some of the variables overlapped: men tended to have higher levels of education (chi-squared test for trend: $\chi^2 = 12.56$, d.f. = 1, $P < 0.01$), as did those from higher social classes (chi-squared test for trend: $\chi^2 = 56.50$, d.f. = 1, $P < 0.01$). Patients who were older, had no educational qualifications, whose social class could not be determined (e.g. long-term retired), who were divorced or separated, and who were female tended to have lower information needs. Patients who were younger, classed as professional or managerial and technical occupations, were married or cohabiting, and male tended to have higher information needs.

Factor 5 (treatment choice) was significantly associated with study location ($F = 8.75$, d.f. = 2, 306, $P < 0.01$), having chemotherapy ($t = 2.68$, d.f. = 307, $P = 0.01$), social class ($F = 3.35$, d.f. = 3, 305, $P = 0.02$) and gender ($t = 2.10$, d.f. = 307, $P = 0.04$). Treatment choice was perceived to be higher at site 1 than at the other two sites, by those who had undergone chemotherapy, those who had professional or managerial and technical occupations, and those who were male patients. Factor 6 (time) was significantly associated with educational qualifications ($F = 4.21$, d.f. = 3, 305, $P = 0.01$) and months since diagnosis ($\tau = 0.09$, $P = 0.02$). Those with higher levels of educational qualifications were more likely to indicate that clinics were too busy to discuss their treatments. Those who had been diagnosed for longer also tended to consider that the clinic was too busy to discuss their condition.

Patient responses to open question

Comments were made on trust in medical expertise and a lack of medical knowledge on the part of patients. Some people took the opportunity to write positive comments on their care while others noted areas of dissatisfaction with care. A number of participants pointed out that they had not received written information and therefore felt unable to comment on this item. In some cases the use of negative statements had been confusing and difficulties were expressed in giving a 'yes' or 'no' response to what was considered a complex area. As one participant wrote 'the answers are not just black and white' [ID C053].

Discussion

Responses to attitude statements indicated that the majority of patients wanted to know what was happening to them and be involved in treatment decisions (94.7%). Although patients wanted to be involved and informed, they did not necessarily express a preference for making treatment decisions, 95.5% reported that they trusted the doctor to decide the best treatment for them. Doctors were perceived to have medical knowledge and so should make treatment decisions. Interestingly, the majority agreed that 'if a doctor tells me everything I am more likely to want to make decisions'. The importance of effective communication in facilitating patient participation in treatment and care decisions has been widely acknowledged in the literature.[3,17,18] Poor communication and inadequate information are the most common complaints by patients with cancer.[18] A recent Australian study reported on the development of a decision aid for patients with locally advanced rectal cancer, designed to assist patients who were considering radiotherapy with or without chemotherapy.[19] Participants in the Australian study commonly reported that they preferred the doctor to take on the role of a decision maker and did not necessarily use information to aid decision making. However, the decision aid was still found to be helpful and a useful tool for increasing understanding. In this study, patients also indicated that information aids decision making, although information may not always be used for decision-making purposes. Effective communication between health professionals and patients is of paramount importance to elicit preferences for participation and involvement in decision making to the degree that patients prefer, to enable patients to feel that their views are valued and to be more expressive during consultations.

Women had more positive opinions on decision making than men and were more likely to prefer active decision-making roles. It has been reported that women are generally more active in seeking health care information; Cancerbackup (Europe's leading cancer information charity) reported that more women accessed their information helpline than men.[20] More women than men are reported to access the Internet for healthcare information.[21] Another study has indicated that men may prefer more passive roles.[5] However, when men with prostate cancer were provided with the information they needed, they assumed a significantly more active role in treatment decision making.[22] Hence the importance of eliciting preferences for information from patients, so that they may engage in the decision-making process if they wish to do so.

Patients generally reported a better understanding of written information than verbal information from doctors. Written information as a supplement to verbal information has a vital role to play, although not all patients had received written information. Patients from higher social classes had a greater understanding of information, while older patients and those who had been diagnosed for longer durations had less understanding of information. However, less understanding does not equate with not wanting information. Older patients may not want to bother doctors and may display a deferential attitude, arising from the traditional paternalistic approach; older patients may not feel able to converse on an equal standing. Therefore, older patients may not receive the information they need and may not understand the information they are given. Time needs to be taken to check understanding using a patient-centred interaction so that patients get the information they need for their own purposes. Doctors can make assumptions about patients based on age and thereby not involve older patients in the decision-making process.[23] This was also a finding from preliminary qualitative work where health professionals talked about the complexities of providing information on treatment choices, particularly in relation to clinical trials.[12] Although age alone is not a valid reason for withholding treatment, elderly patients are often under-represented in cancer clinical trials.[24,25] The reasons for non-inclusion may be many, including strict inclusion criteria that exclude elderly patients or a view by clinicians that elderly patients may not benefit from inclusion.[24] Whatever the reasons, elderly patients may have particular needs for information that are not being met.

Interestingly, patients who were further from diagnosis also had less understanding of information. This may arise because information giving is focused at the time of initial diagnosis and treatment. Information giving should be considered a continuous process, not restricted to one point in time. A recent study on the follow-up care of women with breast cancer has shown how specialist nurses can tailor information to individual needs, providing information when it is needed.[26]

Trusting doctors to make treatment decisions was associated with study location as patients from site 1 (Cancer Centre) were more likely to trust doctors to make decisions. Treatment choices were perceived to be more available at site 1, although this may relate to a greater proportion of people receiving chemotherapy and radiotherapy at this location. Patients with no qualifications were more likely to place trust in medical expertise than those with formal qualifications. Patients who hold such trust may not feel the need to make their own decisions but may still welcome being provided with information and being involved in what is happening to them. For those who hold a degree of distrust, this may reflect a raised public awareness that health professionals are increasingly accountable for their clinical actions, with increased numbers of medical litigation cases reported.

Participating in decision making and meeting information needs are two distinct concepts. While information may be a necessary foundation for decision making it cannot be assumed that those individuals who do not want to make decisions do not want information. Health professionals need to carefully elicit the preferences of patients for both decision-making involvement and information as two distinct components of the shared partnership approach.

The exploratory factor analysis simplified the attitude statements down to a number of important factors. The most important factors related to the areas of decision making, information and trust in medical expertise. This was reassuring as the attitude scale had been designed to incorporate these concepts and the content validity of the scale was confirmed. That is, the scale measured what it had been designed to measure. The attitude scale could be further refined and used in future research to examine the decision-making preferences of people with CRC on a wider basis. A simplified version of the scale could usefully aid clinicians in eliciting preferences for participation and/or involvement in decision making and information. Important factors could be retained and those that were poorly responded to could be eliminated in order to more clearly focus on aspects of the decision-making process.

Limitations

This paper reports on patients' attitudes and views of their participation and involvement in decision making; attitudes do not necessarily determine behaviour. The nature and complexity of the decisions that patients were involved in were not observed and therefore it is not possible to know what occurred during consultations between patients and health professionals; findings are based on reported events. Trust in medical expertise emerged as an important factor but the study did not explore whether trust was maintained when treatment failed. A cross-sectional survey of this nature will capture individual views at one particular moment in time and attitudes may not remain stable over time as they can change depending on context and experiences. A longitudinal approach may have captured how attitudes were altered with new experiences, although this was not possible within the confines of this study because of resource limitations. The structured nature of the attitude scale may be a limitation in that content was interpreted in a way that was not meant. However, the overall combination of qualitative[11,12] and quantitative methods substantially strengthens the conclusions drawn.

Conclusions

There have been few studies that explore the attitudes towards decision making for people with CRC. This study presents new insights into how patients view the concept of participation. Although patients have individual preferences and needs for information there are common areas that justify consideration for heath professionals in engaging patients in the decision-making process. Patients wanted to be informed and involved in decision making but did not necessarily want to take on the role of decision makers. Information had an important role to play but information was not always used to make decisions. Consideration of patient perspectives on involvement in decision making is vital in the light of the current policy imperative in the UK of involving service users in all aspects of care and treatment.

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