

Exploring the decision-making preferences of people with colorectal cancer

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Abstract

Objectives To explore patient views on participation in treatment, physical care and psychological care decisions and factors that facilitate and hinder patients from making decisions.

Design Qualitative study using semi-structured interviews with patients.

Setting and participants Three NHS Trusts in the north-west of England. Theoretical sampling including 41 patients who had been treated for colorectal cancer.

Results For patients, participation in the decision-making process was about being informed and feeling involved in the consultation process, whether patients actually made decisions or not. The perceived availability of treatment choices (surgery, radiotherapy, chemotherapy) was related to type of treatment. Factors that impacted on whether patients wanted to make decisions included a lack of information, a lack of medical knowledge and trust in medical expertise. Patients perceived that they could have a more participatory role in decisions related to physical and psychological care.

Conclusion This study has implications for health professionals aiming to implement policy guidelines that promote patient participation and shared partnerships. Patients in this study wanted to be well informed and involved in the consultation process but did not necessarily want to use the information they received to make decisions. The presentation of choices and preferences for participation may be context specific and it cannot be assumed that patients who do not want to make decisions about one aspect of their care and treatment do not want to make decisions about other aspects of their care and treatment.

Introduction

Establishing preferences for patient participation in decision making is essential if health professionals are to meet the individual needs of patients. To do this effectively it is important to not only discover how patients feel about making decisions but also how health professionals can facilitate this process. At present the concept of patient partnership is considered elusive in practice by some health care providers and requires a shift in power and innovative approaches to empowerment of patients as users of health services. While acknowledging the evolving roles of patients and health professionals, there are concerns about the feasibility of facilitating meaningful patient empowerment.¹

However, shared decision making between patients and health professionals is increasingly advocated as an optimal model.^{2,3} Involving people with cancer in the decision-making process has been shown to be psychologically beneficial,⁴ although there are conflicting findings in this area and the effect may be short lived.⁵ There is contradictory evidence as to what role patients prefer to play in the decision-making process. In a Canadian study involving 1012 women with breast cancer, 66% preferred either active or sharing roles in treatment decision making with younger women, women with higher educational levels and those with earlier stage disease more likely to prefer active involvement.⁶

In contrast, several other studies have reported that people with cancer may not want to be active decision makers.^{7–10} A UK study of 150 women newly diagnosed with breast cancer reported that 52% preferred a passive role in decision making, preferring doctors to make decisions.⁸ Similarly, a study involving 57 Canadian men with prostate cancer found a strong preference (58%) for a passive decisional role.⁹ Interestingly, a subsequent intervention study reported that providing men with prostate cancer with comprehensive support and information could result in preferences for more active decisional roles and reduced anxiety levels,¹¹ suggesting that information and support might be the key to more active decision making.

For people with colorectal cancer a preference for a passive decisional role may be even more pronounced. A small pilot study ($n = 48$) found that over two-thirds of a sample of people with colorectal cancer preferred a passive decision-making role, while 80% perceived that they had not been presented with any treatment options.⁷ In light of patient participation being central to health policies in the UK^{12,13} this strong preference for passive roles and the perception that choices are not offered is arguably a cause for concern. However, there is little to indicate the reasons why people with colorectal cancer may have strong preferences for passive roles in treatment decision making or whether preferences for participation in other types of care decisions (physical and psychological care) would differ. This sort of enquiry requires a qualitative approach to explore the reasons for preferences and the factors that may facilitate or hinder participation.

Objectives

This study aimed to explore the following research questions:

- What sort of treatment and care choices do people with colorectal cancer perceive they are presented with?
- What are patient preferences for participation in different types of treatment and care decisions?
- What are the factors that prevent and enable patient participation in decision-making?

Study design

The study involved a qualitative approach and used semi-structured interviews to explore the views of people treated for colorectal cancer.

Setting and participants

Patients were recruited from three NHS Trusts in the north-west of England (two cancer centres and a large District General Hospital). A diversity of study locations enabled access to

patients with diverse treatment and care experiences. Each Trust provided specialist colorectal cancer services.

Theoretical sampling (sampling with the purpose of answering the research questions) is a particular form of non-probability sampling and was employed in this study.¹⁴ A range of individuals were selected to reflect the total study population and diversity of factors that could influence preferences as well as being theoretically meaningful and directly relevant to the study objectives.¹⁵ A form of quota sampling was used to allow for a range of patients to be included, representative of various stages of the disease and treatment trajectory. Factors taken into consideration when devising sampling quotas were gender, age (< 50, 50–59, 60+), location of cancer (colon, rectal, anal), treatment (surgery, radiotherapy, chemotherapy), presence of stoma, that is a surgical procedure that creates a temporary or permanent opening from the colon/ileum to the surface of the body to function as an anus, stage of disease (newly diagnosed, adjuvant treatment, follow-up, supportive care) and route of referral (GP, emergency). All patients approached to take part in the study were adults (>18 years) who were fully aware of their diagnosis and were considered physically and psychologically able to cope with the interview process.

Access to patients was via hospital outpatient clinics and wards. When suitable patients had been identified, appropriate health professionals acted as intermediaries to gain permission for researchers to approach patients. A letter of introduction was provided. If patients were interested in discussing the study further, a detailed verbal explanation of what participation entailed was provided as well as written information sheets. Although recruitment took place in the hospital environment, interviews were conducted in patients' own homes. Four researchers were involved in conducting the interviews. All four researchers had a nursing background and clinical experience of caring for people with colorectal cancer. Researchers introduced themselves as nurse researchers but

did not interview patients who were known to them from their clinical background.

Ethical approval to conduct the study was obtained from Local Research Ethical Committees (LREC) and Trust R&D departments. All patients who participated were asked to sign consent forms prior to interview and to give written consent for interviews to be audio-recorded, although refusal to give permission for audio recording did not exclude patients from the study.

Data collection

A semi-structured interview guide was designed as the primary data collection instrument. The interview guide defined areas for exploration, but allowed flexibility to diverge in order to pursue emerging ideas;¹⁶ open and closed questions were included.

The interview guide included the following broad sections:

- History of illness
- Participation in treatment decisions
- Participation in physical care decisions
- Participation in psychological care decisions
- Demographic details.

In order to facilitate the interview process, patients were asked initially to briefly recount their health care experiences since diagnosis. This enabled an overall view of treatment received and allowed for a subsequent in-depth exploration of participation in the decision-making process. The interview schedule incorporated three decision-making areas where choices could potentially be made; treatments, physical care and psychological care. Although aspects of physical and psychological care could be considered 'treatment', in this study we defined 'treatment' as active primary treatment for the diagnosis of colorectal cancer that included surgery, radiotherapy and chemotherapy. Open questions were posed to ascertain perceptions of choices, preferences for participation in decision making and factors that helped and hindered decision making in these three areas. A number of closed

questions allowed for the collection of demographic data.

Data analysis

Transcribed interview data were completed in a word processing package (WORD), saved in rich text format and imported into a computer software package for the analysis of qualitative data (N-VIVO), which simplified the physical task of indexing the data and allowed ready retrieval. Data were initially categorized according to responses to questions on the semi-structured interview schedule. Data from each question were then examined systematically using a system of coding to identify particular phenomena and categories of interest.¹⁷

For each interview question an initial phase of coding (open coding) was intended to identify common and disparate views and concepts in patients' responses. In N-VIVO a number of free nodes were initially created to reflect broad ideas, followed by the creation of tree nodes where links between certain ideas became apparent.¹⁸ Four researchers coded data independently and then met to discuss the analysis and reach agreement where ideas and categories overlapped. All four researchers coded data for those interviews they had conducted as well as a selection of interviews they had not conducted. In this way all interviews were coded by at least two researchers.

Sociodemographic and other quantitative data were entered into the data entry spreadsheet component of a statistical software package (SPSS-v10) and descriptive statistics were used to describe study samples and numerical aspects of the data.

Results

The patient sample included both men and women who were mainly aged over 60 years (Table 1). Age ranged from 37 to 84 years, with a mean of 62 years. The majority were married (78%) and white British (88%) and were mainly from social class III (46%) (skilled non-

Table 1 Characteristics of the study sample ($n = 41$)

Variable	<i>n</i>	%
Age		
< 50 years	7	17.1
50–59 years	9	22.0
60+	25	61.0
Gender		
Male	19	46.0
Female	22	54.0
Location of cancer		
Colon	25	61.0
Rectum	13	34.0
Anus	3	5.0
Route of referral		
GP	31	75.6
Emergency	10	24.4
Stage of disease		
Newly diagnosed (3–6 months)	8	19.5
Receiving adjuvant treatment (chemotherapy, radiotherapy)	14	34.1
Routine follow-up (completed all active treatment):		
1–3 years from completion of treatment	6	14.6
3–5 years from completion of treatment	4	9.8
5 years + from completion of treatment	5	12.2
Receiving palliative/supportive care	4	9.8
Stoma		
Temporary (current/previous)	11	26.8
Permanent	7	17.1
Stoma but unknown if temporary or permanent	1	2.4
Never had stoma	22	53.7
Treatment		
Surgery	36	87.8
Radiotherapy	13	31.7
Chemotherapy	28	68.3

manual workers). Lower social classes were under-represented. Only 34% ($n = 17$) of the sample were currently employed, the remaining being either retired or unemployed. This may have been a reflection of the age range of the sample as 49% of the sample were over retirement age (women aged over 60 years and men aged over 65 years).

Time from diagnosis varied from 3 months to 8 years and patients were at various stages of the disease and treatment process (Table 1). Table 1 shows that the majority of the sample had cancer of the colon. Treatment modalities included surgery, chemotherapy and radiotherapy or a combination of treatments. The most common

treatment scenarios were a combination of surgery and chemotherapy (44%) and surgery only (22%). Only one patient was taking part in a clinical trial. Referral to secondary care had been primarily by GP referral (Table 1).

Treatment decisions

Patients perceived that they had been presented with few choices in relation to surgery, particularly if admitted to hospital as an emergency. The perceived life-threatening nature of the initial diagnosis led patients to perceive that surgical treatment was inevitable with few, if any, choices to be made.

Patient - 'I suppose, you know, with the surgery as an emergency, you got to have it done... they had to do it. There are no decisions there you know. If they say something then they're going to do it, because they have to, you know.' (ID209)

The need for surgical intervention was readily understood by patients. It was logical and understandable to a lay person that if cancer was present it should be removed and 'cut out'.

Patient - 'They said it has to be cut out. And I agree with that. It has to be cut out if it's affected, it has to be cut out doesn't it?' (ID103)

Patients perceived that there were more opportunities for participation in decisions related to adjuvant treatment, such as chemotherapy, although the complexities of the treatment often limited their ability to understand the treatment proposed or to make decisions. Expansive drug names presented particular difficulties for patients. Patients perceived that health professionals were understandably busy and would not be able to spend time explaining treatment regimes in detail.

Patient - 'But I think it's too involved I think. Too involved for the layman. They come out with these long words you know the drugs, you know, the names they're about that long and you think what the hell am I on this for? I think it could take a lot of the time up as well. I think there's the doctors time and they're pushed enough as it is ... if they did go into great detail I wouldn't really understand it.' (ID202)

In general, when talking about treatment decisions, patients commented that they were 'told' and 'advised' what treatment would be given rather than offered choices and patients accepted this. The main reasons for such acceptance related to a reported lack of medical knowledge and a trust in medical expertise.

Patient - 'I prefer to leave my treatment decisions up to people that know what they are doing because I'm a lay-man aren't I? Completely ignorant about medical matters so you got to put your trust in medical people haven't you?' (ID105)

Although patients may have been provided with information on different treatment options, patients perceived that there was a 'right' decision to be made and that doctors would make the right decisions for them. The 'right' decision was the one that encompassed the best possible outcome. While patients may have attempted to appraise various treatment options, making the 'wrong' decision was something that patients feared they might do from ignorance of medical matters.

Patient - 'It's a pretty difficult decision, because you don't know what's going to work and what's not going to work so there was one [chemotherapy regime] I asked about, ... every time I asked about it they seemed to steer away from it and I asked them why and they said really they did steer away from it because they didn't think it would be the right one for me anyway. That's why they did steer away from it because they didn't really want me to choose that one but they couldn't say that to me you see.' (ID211)

Those patients who had completed initial treatment and were subsequently in the situation of potentially receiving further non-life threatening and non-urgent treatment, such as reversal of stoma, reported that choices had been available. Patients recalled being asked to decide about reversal of stomas and previous experiences guided their decisions in this area. Returning to a normal life was a commonly sought goal and returning to hospital for further treatment that was not life threatening was not necessarily viewed in a positive light. These aspects of treatment decision making were areas that patients felt they could exert some control.

Patient – ‘The only thing I have had to decide is if I wanted my ileostomy reversed, that were one decision I had to make. ... That would be another major operation which I did not want. But that were a decision, and I were going to have it done weren’t I? ... and then I changed my mind. I don’t know why I changed my mind. I think it were because I were feeling so well, I were back bowling, I were going out, we were going on holiday, we went dancing, and I were feeling grand. I have got a decent quality of life now, I am leaving well alone for a bit longer.’ (ID112)

The majority of patients reported that they would not wish to actually make treatment decisions but they would want to be informed and involved. Involvement related to being kept up-to-date with what was happening and what treatment was planned.

Patient – ‘Yeah, I was involved all the way along. Well they told me like what scans they were doing and why they were doing them. ... I was fully aware of everything that was going on.’ (ID200)

The general consensus was that treatment decisions were best left to doctors as they had the medical expertise: doctors ‘know best’. This view was based on the belief that doctors would provide the treatment that was most beneficial, based on the skills and expertise that they had acquired.

Patient – ‘I wouldn’t like to be too involved about the treatment. I think if they say that treatment is beneficial to you that means you should accept that treatment, you know. I think you should accept the doctor’s (pause). I mean that’s what they’re there for. They know what’s best.’ (ID207)

Patients could find it anxiety provoking if they were expected to engage directly in the decision-making process. Being involved and informed of what was happening was appreciated but being asked to make decisions was not always welcomed. Most patients had confidence in medical expertise and presented a positive view of the expected outcome of treatment, preferring only positive news. However, some patients had experience of health professionals who had expressed uncertainties about the outcome of treatment and uncertainties about how best to proceed, which some patients found disconcerting.

Patient – ‘He said it’s up to you whether you have further chemo... It was awful. I was just, it really threw me when they put the onus back on me whether to have the chemo, because I am one of them, if he had told me you are going to have to have chemo now, I would have done it. But because he made, gave me the decision to it, without sort of saying if you do have it, you know, you will be fine. It’s awful being told, you know, it’s up to me whether I have it.’ (ID209)

While most patients preferred not to make decisions, this was not a unanimous view. There were individuals who wanted to make decisions but found it difficult to communicate with health professionals effectively to obtain the information they needed to make decisions.

Patient – ‘I would like to be fully involved. I would like to be fully consulted, I’d like to have the options explained to me, thoroughly with pro’s and con’s of each and I would like to be able to participate in the decision. Obviously with the advice of the consultant’s and doctors who know more about the diseases and treatments, which I don’t you know. I would like to be err fully participant.’ Researcher – ‘Has that been your experience, that you have been or that you haven’t been?’ Patient – ‘I don’t feel I have been. I feel that err, I think the approach seems to be at each sort of appointment the information imparted is very limited and the attitude seems to be ‘well if the patient doesn’t ask then you don’t need to tell them very much’, keeping very low key or hinting that it’s going alright, that’s fine, and I’ve found that I’ve perhaps asked a bit more than some patient’s and I’ve got some information but there hasn’t been a lot of comfort. It seems to me most doctors are sitting there talking about it and they like to keep you at a distance and give minimal information. Maybe that’s what some people want, people who don’t really want a lot of information, just want to be told everything is alright but I’m not one of those.’ (ID210)

Physical care decisions

Making decisions about aspects of physical care was reported with far less clarity than treatment decision making. When asked about choices relating to physical aspects of care, patients tended to highlight primarily stoma care and diet. Short-term aspects, such as wound care, were perceived as best left for nursing staff to

take responsibility. With physical care it appeared that a combination of nursing staff (stoma care nurses, colorectal specialist nurses, district nurses) shared this responsibility with patients, although patients were unsure as to what decisions had to be made.

For those with a stoma it was more evident that stoma care nurses would need to demonstrate how to care for the stoma and patients would need to develop skills in this area. Stoma formation was a new and unfamiliar experience for patients and a reliance on stoma care nurses in the initial stages to provide advice and support was considered important. Once patients became accustomed to their new situation they began to exert more control over the decision-making process and some sought out information on different aspects of stoma care and began to be more proactive in finding the right sort of appliances and methods of stoma management to suit their own particular lifestyle.

Patient – ‘I was reading in the book when [stoma care nurse] came and I said ‘this irrigation method’ she said ‘Yes’. I said ‘I wouldn’t mind trying that’. I said ‘because you seem to have more freedom with it’ ...She said ‘we will come out and show you how to use it’ and they did. They were brilliant you know. So I only do it Mondays, Wednesdays and Fridays and then on Friday I rest till Monday. Because if it [stoma] wants to work itself over the weekend I let it do that you know, which is brilliant really.’ (ID110)

As diet was a more familiar aspect of daily life, patients felt able to make choices in this area following initial guidance from health professionals.

Patient – ‘I think it would come naturally anyway. I would listen, I would always listen, but I can’t really see me needing a dietician or a you know, somebody to help me look after myself really. I have always done things and I know what’s right and what’s wrong, and I know if I do something wrong, then I know I have done it.’ (ID214)

Written and verbal information had often been given on recommended diets, which patients had followed initially. However, once patients had returned home they began to exert more control over such aspects of care and

tended to modify the advice that was given to suit personal preferences.

Patient – ‘I haven’t been eating maybe quite the right things. I’ve been eating fillet steaks, umm fish I like. I feel that I’m lacking in veg. I should be taking in more green stuff so umm I’m going to have to do that. That’s my own decision. I’m going to eat more bananas. About three a week.’ (ID102)

Psychological care decisions

In contrast to decisions about treatment and physical aspects of care, patients considered that psychological care was their own responsibility. Psychological support was primarily received from close family and friends as well as nurses that patients had formed a close relationship with over the course of their diagnosis and treatment. Patients reported that health professionals did not generally tend to offer psychological support and therefore there were few decisions about psychological care that needed to be made.

Patients spoke of the importance of maintaining a positive attitude and approach to their disease following the initial period of fear and shock at diagnosis.

Patient – ‘It’s always in the back of your mind. It never goes out and you have got to just try and get on with positive aspects in life. The reason for going back to work was to occupy the mind and in that respect it has been a therapy.’ (ID004)

Patients reported problems with sleeping at night, although a prescription for sleeping tablets from GPs was not always considered to be the most helpful approach and patients would find their own ways of dealing with psychological problems.

Patient – ‘He [GP] did offer me some sort of sleeping tablets and this that and the other but I don’t want to get involved in that sort of stuff. I really don’t like taking tablets you know and taking medicine I feel I don’t really need. I mean it was a bit of a problem, you know, sleeping at first, being up all night and things like that. But in the end I just got used to it. I’d stay up the night and I’d have a couple of hours during the day.’ (ID215)

Talking to family and friends in an open and honest manner was considered to be therapeutic.

Patient – ‘I’ve got a lot of friends and people I can talk to although some people get upset emotionally. They get upset when I’ve told people that I have cancer. They are very upset at first ...but then I sort of said to my friends ‘I need to talk about this. I know it’s upsetting you but I need to talk about it.’ So they said ‘oh fair enough.’ I don’t want any sympathy that’s the last thing I wanted, I just want things to carry on as normal, and I want them to know what’s going on as well, because I’m one of these people wears my heart on my shoulder and talks a lot. My friends have been very supportive.’ (ID108)

Patients were aware that professional support was available should they need it but few had utilized such services. While patients were sometimes willing to attend professional counselling sessions and contact specialist nursing services, association with certain services that could represent terminal aspects of care were not always welcome.

Patient – ‘They offered me a Macmillan Nurse right at the beginning. There is no way I’m going to having one of those because I always regard a Macmillan Nurse as ‘that’s it’ you know. You are on your way out.’ (ID216)

Enabling and disabling factors

When asked what factors would enable participation in the decision-making process responses mainly related to being provided with more explanations and information that would enable understanding.

Patient – ‘I think I would really like to know better what’s happening to me in this situation.’ (ID204)

It appeared that information was considered important to build up a knowledge of the disease and to aid understanding rather than being used to inform the decision-making process.

Researcher – ‘Can you think of any ways that you could become more involved or helped to be more involved?’ Patient – ‘Well I think more information. I think err, a clearer discussion with the doctors. ... I don’t want to have a crash course in medicine. I don’t think it’s about, you know,

encroaching other people’s professional territory. Certainly someone like me to build up a knowledge and an understanding of my own illness. And a knowledge and understanding of the treatment and what it’s intended to do and therefore I could become much more part of decisions that might be made because I would actually share with doctors and sharing information about why this or that decision was appropriate.’ (ID210)

Similarly when patients were asked if there was anything that had prevented them from participating in treatment decisions, a lack of information and medical knowledge were the factors most commonly highlighted.

Few patients commented on factors that would enable participation in decisions related to physical and psychological care. Those who did comment reported that more explanations and information on aspects of physical care would have been helpful. Continuity with clinical nurse specialists was reported as an important factor, and knowing that support and advice was available if needed, in particular from stoma care nurses.

Being forewarned about the potential psychological impact at an early stage was suggested by one study participant.

Patient – ‘I was never told what to expect, maybe you could be told a bit more about various things that may or may not happen to you. Because it must effect everybody differently like we said before. Some people must go to pieces whereas other people are pretty okay about it you know. Maybe you should be given a bit, a bit of warning, not say side effects, but warning the effects this news can have on you maybe, because I was never told.’ (ID215)

Discussion

This study explored the views of patients treated for colorectal cancer on their participation in health care decision-making. To patients, participation in decision-making was about being involved in the consultation process and being provided with information at various stages of care and treatment. In previous quantitative studies ‘active participation’ has been described

in terms of patients making decisions but in this study patients could perceive they had been participant by virtue of being fully informed and kept up to date with what was happening to them. Being involved did not necessarily indicate that patients would want to make decisions. Previous studies describe patients as 'passive' if they do not want to make decisions but this may not be appropriate terminology to describe what patients feel about their involvement in the decision-making process. A shared decision-making model with patients and doctors as equal partners who exchange information and share preferences for treatment and negotiate a mutually acceptable decision may be far too simplistic an approach.¹⁹ Greater conceptual clarity is needed to clarify what is meant by patient participation.

Patients perceived that there were few choices to be made about surgical treatment, although patients could clearly understand the need for surgery. Removing a tumour by cutting it out was readily understandable to the layperson. Interestingly, while patients perceived that there were more choices to be made about adjuvant treatment, the complexities of chemotherapy regimes presented problems for patients in understanding the information they were given. Hence, this presents further challenges to health professionals who need to be aware that adjuvant treatment warrants more attention with respect to the provision of information to patients and checking for understanding.

Treatment decisions were often seen as 'right' or 'wrong' by patients, although in reality this is not always the case. Guidelines on the management of colorectal cancer acknowledge that there is less reliable evidence for the effective management of this disease than for other cancer conditions.²⁰ Patients would comment that they felt there was a right decision and they had to find that right decision. This could raise anxieties for those patients who then tried to come to a decision that they knew health professionals would approve of and consider to be the right choice. It is perhaps not surprising in this case that patients may be reluctant or uneasy to actually make decisions for fear of

making the 'wrong' decision, preferring instead to place their trust in health professionals.

Patients expressed preferences for being involved in decisions relating to physical and psychological care. With physical care, the main areas highlighted were stoma care and diet. Patients acknowledged that there were few real decisions to be made but there were skills to be learnt and information to be acquired that would allow them to build up an understanding and knowledge base that would be available to them in the future. As stomas were permanent for many patients, developing skills in stoma care management was essential. Nurse specialists were key to enabling patients to develop the skills and knowledge base that they needed. This is an important point as the NHS Cancer Plan states that new investment in training and support in palliative care will be provided for community nurses to extend the support available for people living with cancer in primary care.¹²

Interestingly, patients perceived that psychological care was their own responsibility. Maintaining a positive attitude was considered important and patients relied on family and friends for psychological support. Whether patients actually perceived that it was important to be positive or whether they simply reported what they considered was expected of them was not explored. Previous work with women with breast cancer has indicated a positive attitude as a way of coping with the cancer diagnosis and may reflect a specific cultural view held in the UK.²¹ Little mention was made of professional psychological support services. If family and friends are so valued for their support in this area perhaps health professionals need to encourage more family involvement in consultations. In addition, if relatives and friends are providers of psychological support there is a need for health professionals to attend to the support needs of those affected by cancer.

Barriers to involvement in decision making related to a lack of information and inadequate medical knowledge among patients. The provision of information is an area that can be addressed and interventions have demonstrated

that participation and/or involvement in health care decision making can be increased with appropriate intervention strategies. Lack of medical knowledge is difficult to address. Trust in medical expertise was an important factor and should not be underestimated in terms of patient's satisfaction with their level of involvement. Most patients in this study appeared satisfied with their level of involvement based on trust in medical expertise.

Limitations

This study had a small sample size, which limits the generalizability of findings. However, the qualitative design of this study did allow for important insights to emerge from a broad and purposely selected sample of people with colorectal cancer.

Time from diagnosis for patients in this study varied from 3 months to 8 years and, for those patients who were a number of years from diagnosis, recollections may have been altered or distorted with the passing of time. However, it was considered important to allow patients to reflect on their broad and differing range of experiences and not to limit the enquiry to those who were newly diagnosed.

There was no intention to exclude ethnic minority groups but the majority of the sample were White British and the findings therefore do not represent the views of ethnic minorities. People from lower social classes were also underrepresented in this study and this factor may have biased findings.

Only one patient was involved in a clinical trial and this is not representative of people being treated for colorectal cancer in the UK. It would be interesting to conduct further research to investigate patient involvement in decisions related to entry to clinical trials.

Conclusions

Patients in this study wanted to be involved and informed but did not necessarily want to make decisions. However, it should not be assumed that patients who do not want to

make decisions about one aspect of their care and treatment will not want to make decision about other aspects of their care and treatment. In this study patients were more able to engage in the decision-making process in respect to decisions about radiotherapy and chemotherapy than about surgical treatment and were more able to engage in decisions about physical and psychological aspects of care than treatment decisions. Health professionals need to elicit preferences for various aspects of care and not assume that an initial passive preference in relation to surgical treatment implies a passive preference for all other types of health care decisions. Patients may be more confident in making decisions in areas where there is familiarity. Information and checking of understanding are central to providing patients with a real choice as to whether to participate in decisions about treatment.

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